House of Commons
Health Committee

The Electronic Patient Record

Sixth Report of Session 2006–07

Volume I

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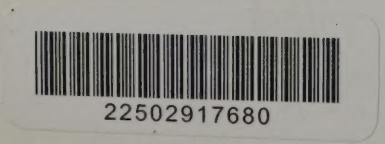

House of Commons
Health Committee

The Electronic Patient Record

Sixth Report of Session 2006–07

Volume I

Report, together with formal minutes

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Footnotes

In the footnotes of this Report, references to oral evidence are indicated by 'Q' followed by the question number, and these can be found in HC 422–III. Written evidence is cited by reference in the form 'Ev' followed by the page number; Ev x for evidence published in HC 422–II on 25 April 2007, and Ev x (HC 422–III) for evidence published in HC 422–III on 13 September 2007.

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Summary

Electronic patient record (EPR) systems have the potential to bring huge benefits to patients and are being implemented in health systems across the developed world. Storing and sharing health information electronically can speed up clinical communication, reduce the number of errors, and assist doctors in diagnosis and treatment. Patients can have more control of their own healthcare. Electronic data also have vast potential to improve the quality of healthcare audit and research. However, increasing access to data through EPR systems also brings new risks to the privacy and security of health records.

In England, implementing EPR systems is one of the main aims of the 10-year National Programme for Information Technology (NPfIT), which was launched in 2002, building on earlier initiatives. The main plank of the NPfIT programme is the NHS Care Records Service (NCRS) which will create two separate EPR systems: a national Summary Care Record (SCR), containing basic information, and local Detailed Care Records (DCRs), containing more comprehensive clinical information. NCRS will also include a Secondary Uses Service (SUS) which will provide access to aggregated data for management, research and other 'secondary' purposes.

Following delays, trials of the SCR are now taking place at a number of 'early adopter' sites. We found it difficult to clarify exactly what information will be contained in the SCR and what the primary uses of the record will be. The explanations eventually provided by the Department of Health showed that the SCR could have great clinical value in some situations. Therefore, although it will be less comprehensive than clinically rich DCR systems, we support the implementation of the SCR as soon as possible.

The consent arrangements for creating and adding information to the SCR have not been well communicated to patients or clinicians. In particular, debate has arisen over whether an 'opt-out' or 'opt-in' system should be used. In fact, a hybrid consent system is now proposed: an 'opt-out' system will be used for the creation of the SCR, while the addition of clinical information will happen on an 'opt-in' basis. This is a satisfactory consent model but we recommend that much more is done to explain these arrangements, particularly to patients.

Important components of the SCR have not yet been completed. "Sealed envelopes" will allow patients to restrict access to particularly sensitive information and are an important safeguard for patient privacy. Meanwhile the HealthSpace website will allow patients to access their SCR from home and has great potential for making care more patient-centred. We therefore recommend that both "sealed envelopes" and HealthSpace are implemented as soon as possible. We also make specific recommendations for improving these features of the SCR.

Maintaining the security of the SCR and other NCRS systems is a significant challenge. Each SCR will be potentially available across the country to a wide range of different users, making operational security especially problematic. Connecting for Health, the organisation responsible for delivering NPfIT, has taken significant steps to protect operational security, including strong access controls and audit systems. However, the

impact of these measures in the complex environment of the NHS is difficult to predict. We recommend a thorough evaluation of operational security systems and security training for all staff with access to the SCR.

DCR systems, which will allow local organisations to share detailed clinical information, are the "holy grail" for NPfIT. Such systems can improve safety and efficiency, support key activities such as prescribing, and vastly increase the effectiveness of clinical communication. In particular, DCR systems offer improvements to the care of patients with multiple or long-term conditions. It is on NPfIT's success in delivering DCR systems that the programme's effectiveness should ultimately be judged.

In order to deliver DCR systems, Connecting for Health has set out to replace local IT systems across the NHS, as well as building the capacity to link these systems together. The new national broadband network has now been completed, but progress in other areas has been disappointing. In particular, the introduction of new basic hospital Patient Administration Systems (PAS) has been seriously delayed. One of the two main hospital PAS products, Lorenzo, will not be trialled in the NHS until 2008. As a result of these and other delays, it is not clear when joined-up DCR systems will be widely available.

In addition, we found it difficult to ascertain either the level of information sharing that will be possible when DCR systems are delivered, or how sophisticated local IT applications will be. In its original specification documents in 2003, NPfIT established a clear vision for local electronic records systems. Four years later, however, the descriptions of the scope and capability of planned DCR systems offered by officials and suppliers were vague and inconsistent. Some witnesses suggested that parts of the original vision have been abandoned because of the difficulties of implementing new systems at a local level. We recommend that Connecting for Health publish clear, updated plans for the DCR, indicating whether and how the project has changed since 2003. We also recommend that timetables for completing DCR systems are published by all suppliers.

An important cause of the delays to DCR systems has been the lack of local involvement in delivering the project. Hospitals have often been left out of negotiations between Connecting for Health and its suppliers, and found themselves, as one witness put it, at "the bottom of the food chain". As a result, they have lacked the incentives or enthusiasm to take charge of deployments. Increasing local ownership is now a key priority for the programme. The NPfIT Local Ownership Programme is an important first step but does not go far enough. We make a number of detailed recommendations for increasing local ownership, including giving local organisations responsibility for negotiating with suppliers and for contract management, and offering users a choice of systems wherever possible.

We recommend that Connecting for Health switch as soon as possible to focus on setting and ensuring compliance with technical and clinical standards for NHS IT systems, rather than presiding over local implementation. Clear technical standards will allow systems to be centrally accredited for use in the NHS, whilst giving local users the final say over which system is procured and how it is implemented. The GP Systems of Choice initiative is a good model for this approach. We also recommend that an independent technical standards body and a standards testing service be established to support this work.

Safe and effective data sharing, the fundamental aim of DCR systems, also requires a more standardised approach to the recording of clinical information. To this end, the agreement on a universal coding language for the NHS, SNOMED-CT, and a single unique patient identifier, the NHS number, are important achievements. We recommend that clear timetables are set for introducing SNOMED-CT and the NHS number across the health service. In addition, we recommend that Connecting for Health work with professional bodies to develop information standards for the recording of clinical data in the various specialities and care settings across the NHS.

The development of the SCR and DCR will offer the SUS access to clinical data which are more timely, better integrated and of a significantly higher quality than those currently available. This is likely to transform the SUS and offers significant benefits, most notably for health research. However, researchers told us that more should be done to ensure that these opportunities are maximised. We make several recommendations for improving access to data for research purposes, including not only the single unique identifier, but also developing better linkage between new and existing databases.

Increasing access to patient data also brings new challenges for safeguarding patient privacy, however. There is a difficult balance to be struck between the need to protect privacy and the opportunities for research, between safeguarding individual rights and promoting the public good. There are also a number of weaknesses within current access and governance systems. In particular, during the inquiry questions were raised about the extent to which pseudonymisation of data should be relied upon to protect privacy. We recommend that the Department of Health conduct a full review of both national and local procedures for controlling access to electronic health data for 'secondary uses'.

Despite some notable successes, the delivery of NCRS has in general been hampered by unclear communication and a worrying lack of progress on implementing local systems. Although Connecting for Health's centralised approach has brought important benefits, it will increasingly need to be modified, particularly if the crucial DCR programme is to succeed. By clearly restating its aims, providing timetables and indicating how they will be met, and ensuring local organisations take charge of deployment, Connecting for Health can still ensure that NCRS is a success.

1 Introduction

1. An important aim of most developed health systems is the creation, expansion and linkage of electronic patient record (EPR) systems. The introduction of EPR technology offers numerous and significant benefits. Storing and transferring patient information electronically has the potential to significantly reduce clinical errors and improve patient safety as well as allowing clinicians to communicate more quickly and accurately and to identify relevant information more easily. Good EPR systems can increase efficiency, reduce duplication and waste, and improve the cost-effectiveness of health services. EPR systems can also make information much more readily accessible to patients, allowing them to assume more control over their health records and thereby become more active in their own care. In addition, electronic databases of health information can be used for a range of purposes other than direct care provision, for example clinical audit and research. It is right to describe EPR as "potentially a transformative technology".[1]

2. However, alongside these new opportunities, EPR systems also bring new risks, particularly to the privacy and safety of health information. Electronic systems allow access to data from many locations, increasing the likelihood of a security breach; they can also give individuals access to much more data than was previously possible, increasing the damage caused by system misuse. Personal health information is often highly sensitive, and it is therefore difficult to repair the damage caused by a breach of privacy. All these risks can be mitigated, but there is little doubt that EPR systems will create, as the European Data Protection Working Party acknowledged, "a new risk scenario" for personal health information.[2]

3. In the NHS in England, the development of EPR systems was given central direction and impetus by the instigation of the 10-year National Programme for Information Technology (NPfIT), the largest civilian IT project in the world, in 2002. In developing EPR systems, England is firmly in line with trends in the developed world: EPR systems are being created in various forms in the USA, Canada and Australia, as well as in Scotland, Wales and many countries in the European Union.

4. The NHS Care Records Service (NCRS), and the infrastructure upgrades required to support it, are the central plank of the NPfIT project and account for the majority of planned expenditure. While most GPs and hospitals have long been using IT systems for a range of purposes, including patient record storage, NCRS seeks to expand and link together electronic data about patients, as well as significantly upgrading hardware, software and network infrastructure. Upgrading, replacing and linking existing records systems is intended to lead to the creation of electronic Detailed Care Records, available across local health economies. NCRS will also provide a separate Summary Care Record for each NHS patient, available throughout England.

5. While the benefits of EPR systems are widely acknowledged, NPfIT's implementation, and particularly the delivery of NCRS, has recently been subject to widespread questioning

1 Ev 81

2 See European Data Protection Working Party, *Working Document on the processing of personal data relating to health in electronic health records (EHR)*, 00323/07/EN, WP131, p.5

and criticism. Delays of at least two years have affected the Summary Care Record project and the upgrades to Patient Administration Systems (PAS) required to support the Detailed Care Record. A report by the National Audit Office in June 2006 praised NPfIT's initial contracting arrangements but criticised the lack of information about when new systems were likely to be implemented. In March 2007, the Public Accounts Committee concluded that there is still "much uncertainty" about when and what NPfIT will deliver, highlighting ongoing delays to NCRS. Meanwhile, the piloting of the new Summary Care Record system, which began in spring 2007, has sparked public debate about the privacy and security of the new systems. Academics, the media and growing numbers of clinicians and patients have all expressed serious doubts about the organisation and performance of NPfIT.

6. In light of these wide-ranging and serious concerns, and of the great benefits to patient care offered by EPR systems, the Committee decided in February 2007 to hold an inquiry. Rather than examining the whole of the NPfIT project, we chose to focus on the NCRS project, the most expensive, most ground-breaking and most controversial element of the programme. Our terms of reference were as follows:

- What patient information will be held on the new local and national electronic record systems, including whether patients may prevent their personal data being placed on systems;
- Who will have access to locally and nationally held information and under what circumstances;
- Whether patient confidentiality can be adequately protected;
- How data held on the new systems can and should be used for purposes other than the delivery of care e.g. clinical research; and
- Current progress on the development of the NHS Care Records Service and the National Data Spine and why delivery of the new systems is up to two years behind schedule.

7. The Committee received more than 70 written evidence submissions from academics, lawyers and IT companies, as well as a number of staff and patient groups. The Department of Health provided an initial memorandum in March 2007 and sent additional submissions on 12 June and 16 July. We held oral evidence sessions between April and June 2007, hearing from, amongst others, civil servants, doctors, lawyers, IT suppliers, patient groups, the Assistant Information Commissioner and the Minister of State for Quality. The Committee also visited Nashville, Ottawa, Amiens, Paris and Hackney in order to look at and discuss EPR systems.

8. Our report considers the issues raised by the inquiry under the following headings:

- Overview of EPR systems;
- The Summary Care Record;
- The Detailed Care Record; and

- The Secondary Uses Service.

9. The Committee would like to thank those who submitted evidence and those we met during our visits, as well as the staff of the Foreign and Commonwealth Office who made these visits possible. We are particularly grateful for the expert advice which we received from our specialist advisors Professor Ross Anderson, Dr Jem Rashbass and Professor John Williams.

2 Overview of EPR systems

Background

10. NHS organisations have long made use of a wide range of IT systems. However, levels of computerisation have generally varied considerably between, and often within, organisations and tiers of care. As a broad outline, the following characteristics have been typical:

- **General practitioners** have had the highest level of computerisation with the vast majority of surgeries using IT systems both for administrative and clinical purposes. Most practices have stored some patient information electronically, and many have dispensed with paper systems altogether after scanning old paper notes into new electronic systems. The new GMS contract, introduced in 2004, consolidated the high level of IT usage in general practice by requiring payments and performance assessment to be processed electronically.[3]

- In **hospitals**, the level of computerisation has varied widely but has been consistently lower than in general practice. All NHS hospitals have used basic Patient Administration Systems (PAS) for a number of years for administrative purposes such as scheduling, recording admissions and discharges, and storing patient demographic and basic diagnosis information. In some clinical areas, such as theatres and pathology, more sophisticated systems have often been used for both administrative and clinical purposes. However, the use of more complex systems capable of recording all aspects of clinical care has been extremely rare, and the overwhelming majority of patient records have been stored in often voluminous paper notes.[4] The lack of unifying standards and a piecemeal approach to procurement has meant that IT systems in different departments within a single hospital have often been unable to communicate with each other.

- Amongst **community and mental health care providers**, levels of IT use have been the lowest of all. Many such organisations have not used computers even for administrative purposes and have stored all patient records on paper.[5]

- More complex systems have been developed in some parts of the country across **clinical networks** with responsibility for a particular patient group. For example, shared databases and other IT systems have been used at local level by cancer, diabetes and renal networks.

11. In general NHS IT systems have been characterised by an inability to share information between different organisations, between primary and secondary care, and often between

3 Under the GMS contract, responsibility for supplying GP IT systems was passed from individual practices to PCTs.

4 There have been some exceptions to this rule, for example the successful implementation of the Millennium system at Homerton and Newham hospitals in London and the installation of EPR systems at the Wirral Hospital – see Q 577.

5 Q 27

different parts of the same organisation. The situation was likened by one witness to a series of "electronic islands" with little ability to communicate.[6]

12. In 1998, the Government launched an NHS information strategy, *Information for Health*. The strategy was intended to run until 2005 but was superseded in 2002 by NPfIT. *Information for Health*'s goals included:

- The creation of an electronic health record, containing "lifelong core clinical information" for each NHS patient, by 2005, developed initially by linking local primary care systems; and
- Establishing "level 3" electronic patient record systems in all hospitals by 2005 (to include electronic ordering, reporting, prescribing and care management).[7]

The National Programme for Information Technology

13. In June 2002, the Department of Health published *Delivering 21st century IT support for the NHS: national strategic programme*, effectively the blueprint for the National Programme for Information Technology (NPfIT). The strategy restated the importance of the goals set out in *Information for Health* but acknowledged that progress had been hampered by lack of protected funding, lack of central direction, poor value for money and a shortage of network capacity.[8]

14. *Delivering 21st Century IT* proposed to address these problems through a more centralised, national approach to NHS IT, linked to the ambitious goals and generous funding increases embodied in the 2000 *NHS Plan*.[9] The document stated:

> The core of our strategy is to take greater central control over the specification, procurement, resource management, performance management and delivery of the information and IT agenda. We will improve the leadership and direction given to IT, and combine it with national and local implementation that are based on ruthless standardisation.[10]

What NPfIT aims to deliver

15. The initial aims of the project were to establish three main systems:

- An Electronic Transfer of Prescription service (ETP);
- An electronic appointment booking service (subsequently expanded in scope to become Choose and Book); and

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6 Q 102

7 NHS Executive, *Information for Health: An Information Strategy for the Modern NHS 1998-2005*, September 1998, p.110. The strategy set out 6 different levels of EPR to be achieved by hospitals, ranging from level 1, "Clinical Administrative data", through to level 6, "Advanced multimedia and telematics", p.37.

8 Department of Health, *Delivering 21st Century IT support for the NHS: national strategic programme*, June 2002, p.1

9 Ibid, p.1

10 Ibid, p.i

- The NHS Care Records Service (NCRS), including a detailed electronic patient record to be shared by local organisations and a summary record, available nationally.[11]

16. The programme's initial aims also included major upgrades to existing software and network infrastructures, including the following:

- The creation of a private broadband network to link all NHS organisations to the national system, known as the New National Network for the NHS (N3);
- The development of a National Data Spine to store information centrally, to link local and national IT systems and to host national systems such as the Summary Care Record; and
- The widespread installation, replacement or upgrading of basic computer systems across the NHS, including PAS software for hospital and community providers and new or upgraded systems for GPs.

17. In order to achieve these goals, the Department of Health agreed a number of contracts with a range of private suppliers in 2003 and 2004. The main contracts are shown in the table below:

Service	Scope	What it does	Contractor	Date Agreed	Value (£m)
New National Network for the NHS (N3)	National	Fast and reliable network to enable communication within and between NHS organisations. The foundation of the rest of the NPfIT project.	British Telecom	Feb 2004	530
National Data Spine	National	Database which holds patient demographic information, national electronic patient record (Summary Care Record) and enables communication between national and local NPfIT systems.	British Telecom	Dec 2003	620
Choose and Book	National	Links GP and hospital systems to allow electronic booking of appointments.	Atos Origin	Oct 2003	64.5
NHSmail	National	NHS-wide e-mail service.	Cable & Wireless	July 2004	50-90
Local Service Provider – North East	Regional	Provision of NHS Care Records Service, new Patient Administration Systems and prescribing (ETP) systems across the region.	Computer Sciences Corporation (Accenture until Sep 2006)	Dec 2003	1,100
Local Service Provider –	Regional	Provision of NHS Care Records Service, new Patient	British Telecom	Dec 2003	996

11 Full details of the original specification for the NCRS, which also included a range of local clinical IT systems, can be found at National Programme for Information Technology, *Output Based Specification Version Two, Integrated Care Records Service*, 1 August 2003.

London		Administration Systems and prescribing (ETP) systems across the region.			
Local Service Provider – Eastern and East Midlands	Regional	Provision of NHS Care Records Service, new Patient Administration Systems and prescribing (ETP) systems across the region.	Computer Sciences Corporation (Accenture until Sep 2006)	Dec 2003	934
Local Service Provider – North West and West Midlands	Regional	Provision of NHS Care Records Service, new Patient Administration Systems and prescribing (ETP) systems across the region.	Computer Sciences Corporation	Dec 2003	973
Local Service Provider – South	Regional	Provision of NHS Care Records Service, new Patient Administration Systems and prescribing (ETP) systems across the region.	Fujitsu	Jan 2004	996

Table 1: Main NPfIT contracts
Source: National Audit Office

18. Since 2002, the scope of NPfIT has increased as a number of additional services have been added to the original specification. These include:

- Digital capture and storage of X-rays and other diagnostic results through the installation of Picture Archiving and Communications Services (PACS) in acute hospitals;
- Automation of assessment of GP practice performance against the new GP contract using the Quality Management Analysis System (QMAS); and
- A system (known as GP2GP) for moving patients' GP records instantly from one practice to another when a patient switches practice.

How the programme is organised

19. In contrast with previous NHS IT strategies, NPfIT involves the procurement of new systems and services at a national level rather than by individual NHS organisations. In 2005, responsibility for NPfIT was transferred from the Department of Health to an arms-length body, NHS Connecting for Health. Thus all of the contracts listed in table 1 were agreed on behalf of the NHS by the Department of Health and are now held and managed by Connecting for Health. The majority of new systems will be installed in local NHS organisations, but suppliers are answerable to Connecting for Health, a national organisation. Connecting for Health is currently transferring some responsibility for contract management to the 10 regional Strategic Health Authorities (SHAs) through the NPfIT Local Ownership Programme (NLOP), which we discuss in Chapter 4.

20. Since its inception, the project has been headed by Richard Granger, inaugural Director General for IT in the NHS. Mr Granger announced in June 2007 that he would leave his post by the end of the year.[12]

21. Department of Health and Connecting for Health officials praised the centralised organisation of the programme, arguing that the introduction of national-level procurement in 2002 had led to a step change in progress on the delivery of new IT systems to the NHS. They pointed out that the centralised approach had led to:

- Better **value for money** because of national procurement: officials argued that local procurement of systems had generally proved unaffordable in the past;[13]
- Much more **consistent development** of IT across the NHS, in contrast with the previous "electronic islands";[14]
- Greater potential for **interoperability** between systems than if a more localised approach had been taken.[15]

22. Defending the centralised approach to the programme, Richard Granger was especially critical of progress prior to the inception of NPfIT:

> ...the progress that had been made was lamentable—and yet at very significant cost of about a billion pounds a year at 2002. The revisionists are busy at work now trying to make out the progress that had been achieved before 2002 was extremely good and has somehow been retarded by the introduction of national systems; but the evidence does not substantiate that viewpoint.[16]

23. As table 1 demonstrates, some of the main NPfIT contracts cover services to be provided nationally across the whole of the NHS, such as the N3 network and the National Data Spine (which includes the Summary Care Record). Contracts are also in place for the provision of services across regional areas. For this purpose, the NHS was divided into five geographical 'clusters', for each of which a Local Service Provider (LSP) contract was agreed. LSPs were contracted to provide a wide range of services to organisations across their 'cluster', including new PAS systems and the other services which will contribute to the Detailed Care Record. The five LSP contracts made up 80% of the value of the initial contracts (around £5 billion of the total value of £6.3 billion). The five 'clusters' and their LSPs are shown below:

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12 See *Personal statement regarding Richard Granger*, Connecting for Health press release, 6 June 2007

13 Q 578

14 Q 2

15 Q 587

16 Q 2

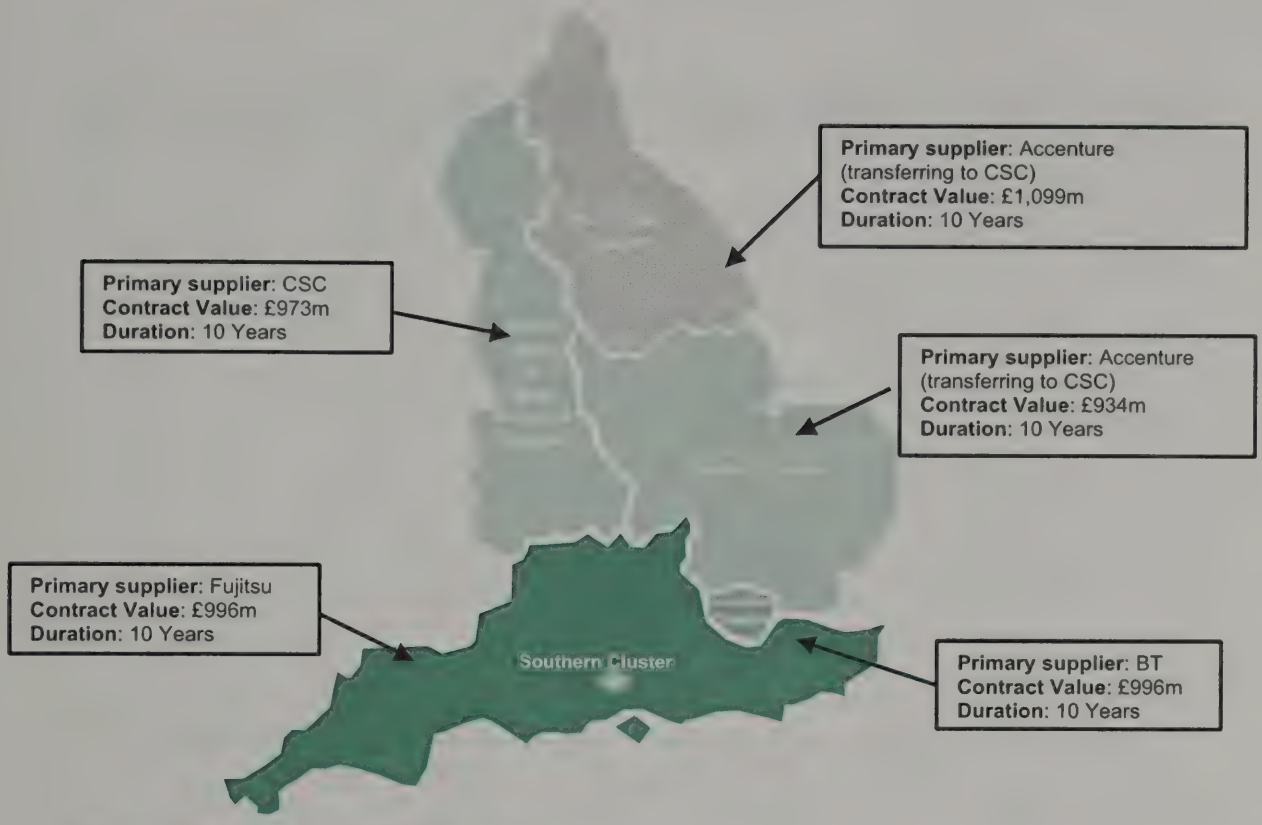

Figure 1: The 5 regional NPfIT 'clusters'

24. The five LSP contracts were originally awarded to four different suppliers, with Accenture holding two of the five contracts. However, Accenture withdrew from the programme in September 2006 and its two LSP contracts were transferred to Computer Sciences Corporation (CSC), one of the existing LSPs.[17] Thus CSC now holds three of the five LSP contracts with the others continuing to be held by Fujitsu and BT. BT also holds the two major contracts for supplying services at a national level, those for the N3 network and the National Data Spine.

25. LSPs have subcontracted some areas of their work to smaller, more specialised companies. In particular, the development of new PAS software for hospitals and community care providers has generally been outsourced. In the three clusters now under CSC, the Lorenzo PAS system is being provided by iSoft, a UK software firm.[18] In the London and Southern clusters, a Common Solution Project was initially formed between BT and Fujitsu to procure PAS systems from the US software supplier IDX. However, the partnership was subsequently dissolved and both LSPs subsequently switched from IDX to another US firm, Cerner, as their main PAS system supplier.[19] Cerner will supply the Millennium PAS system.[20]

26. The current suppliers for new hospital PAS software are shown in the table below:

17 See *Changes to delivery of NHS National Programme for IT,* Connecting for Health press release, 28 September 2006

18 Q 256

19 Q 376

20 Q 389

Cluster	Local Service Provider	PAS system	PAS system supplier
London	BT	Millennium	Cerner (IDX until July 2006)
Southern	Fujitsu	Millennium	Cerner (IDX until April 2005)
Eastern	CSC	Lorenzo	iSoft
North East	CSC	Lorenzo	iSoft
North West & West Midlands	CSC	Lorenzo	iSoft

Table 2: Hospital PAS suppliers by cluster
Source: National Audit Office

Progress to date

27. Assessments of NPfIT's overall progress to date have varied widely. The Department of Health's evidence submission provided an upbeat assessment of progress:

> [NPfIT] is already providing essential services to support patient care and the smooth running of the NHS, without which it could not now properly function. Installation of a modern, high speed, secure infrastructure and national network [N3] has been completed ahead of schedule and is daily supporting millions of business transactions in the NHS...Widespread coverage of Community Patient Administration Systems has been achieved where nothing existed before. Over half of hospitals now have digital x rays and scans.[21]

28. Richard Granger offered the Committee a range of statistics to demonstrate the scale of progress:

> We now have 19,000 places connected up, so we have one of the biggest virtual private networks on the planet and people take that for granted. We are now computerising, to deliver prescriptions safely, 200 GP practices a week with the relevant software. We typically move 120,000 prescriptions electronically now on any given day. About every 10 seconds a patient gets a booking completed electronically.[22]

29. Evidence from suppliers was equally positive about progress. BT, both the supplier of the main national systems and the LSP for London, provided a clear timetable for completion of their contracted elements of the programme:

> The foundations of the NPfIT system provided by BT are now built, operating and secure. Culturally integrating these systems so they become second nature for NHS

21 Ev 1
22 Q 2

> staff is well underway. Over the next five years, the goal is to complete this programme.[23]

30. A report by the National Audit Office (NAO), published in June 2006, however, was notably less bullish. While commending the "substantial progress" achieved by the programme, the NAO also acknowledged that implementation "continues to present significant challenges".[24] In particular, the NAO report highlighted:

- delays of ten months to the delivery of the National Data Spine and around two years to the launch of the Summary Care Record, both the responsibility of BT;[25] and
- delays of between one and two years to the delivery of systems by LSPs.[26] The Department of Health has acknowledged that the installation of new hospital PAS systems, one of the key responsibilities of the LSPs, is now "up to two years behind schedule".[27]

31. The subsequent report from the Public Accounts Committee (PAC), published in March 2007, expressed further doubts. In particular, the PAC highlighted:

- Two-year delays to both the national and local elements of the NHS Care Records Service, pointing out that "no firm implementation dates exist" for these elements of the programme;
- The failure to quantify the benefits which the programme will deliver;
- A lack of capacity amongst suppliers, exacerbated by the withdrawal of Accenture, and an over-reliance on two main software suppliers, Cerner and iSoft, for delivery of key elements of the programme;
- The lack of effective communication with clinicians by NPfIT's leaders and failure to clarify the roles of local NHS organisations in the delivery of the programme; and
- A narrow focus on the delivery of new systems rather than the "broader process of business change" required to maximise benefits.[28]

The PAC concluded that,

> At the present rate of progress it is unlikely that significant clinical benefits will be delivered by the end of the contract period.[29]

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23 Ev 47

24 National Audit Office, *Department of Health: The National Programme for IT in the NHS*, HC 1173, 16 June 2006, p.6

25 Ibid, p.4

26 Ibid, pp.18–23

27 Ev 9

28 Public Accounts Committee, Twentieth Report of Session 2006-07, *Department of Health: The National Programme for IT in the NHS*, HC 390, pp.5-7

29 Ibid, p.6

32. Estimates of the likely overall costs of the programme have also varied substantially. As shown in table 1, the cost to the NHS of the main initial contracts will be £6.3 billion over the 10 years of the contract. However, the NAO estimated in its report that the total cost of implementation, including expenditure by local organisations, will be £12.4 billion.[30] In its response to the Health Committee's 2006/7 Public Expenditure Questionnaire, the Department of Health estimated the total net cost of NPfIT at £7.5 billion, after accounting for an estimated £4.2 billion of cost savings as a result of the national programme.[31]

The NHS Care Records Service

33. At the heart of NPfIT is the NHS Care Records Service (NCRS), a set of projects which eventually aim to provide detailed electronic patient records across the NHS which can be shared between different clinicians, organisations and tiers of care. The majority of the expenditure on the programme, including the creation of the National Data Spine and the replacement of local PAS systems across the NHS, is in support of the NCRS. As the PAC put it, the NCRS is "central to obtaining the benefits of the programme".[32] The Department of Health described NCRS as the "cornerstone" of NPfIT.[33]

What NHS Care Records Service aims to deliver

34. The NCRS will be made up of a group of systems with distinct functions and purposes. These are:

- The **Personal Demographics Service** (PDS), an application supported by the National Data Spine, which is already in widespread use.[34] The PDS contains basic demographic details about every NHS patient including name, address, date of birth, NHS number and current GP.[35]

- The **Summary Care Record** (SCR), which is also supported by the Spine and is currently being piloted in the Northwest. The SCR will be a high-level record of key clinical information including allergies, prescriptions, summary medical history, operations and procedures. An SCR will be created for every NHS patient, although patients can choose to opt out, and will be potentially available throughout England. We examine the SCR in Chapter 3.[36]

- **Local record systems**, on which comprehensive patient records will continue to be stored in hospitals, GP surgeries and other organisations. Many of these systems will be replaced or upgraded as part of NPfIT and paper systems will increasingly

30 National Audit Office, *Department of Health: The National Programme for IT in the NHS*, HC 1173, 16 June 2006, p.4

31 Health Committee, *Public Expenditure on Health and Personal Social Services 2006: Memorandum received from the Department of Health containing Replies to a Written Questionnaire from the Committee*, HC 1692–i, p.102

32 Public Accounts Committee, Twentieth Report of Session 2006–07, *Department of Health: The National Programme for IT in the NHS*, HC 390, p.5

33 Ev 117 (HC 422–III)

34 See Ev 4–5: the Department of Health described the PDS as a "key component" of NCRS and stated that the system already transfers 6.5 million messages per week to and from users across the NHS.

35 The PDS replaces the National Strategic Tracing Service, which had many similar functions.

36 Ev 5

be replaced by electronic systems. In hospitals, for example, new PAS systems will be installed to fulfil a range of largely administrative functions, followed by more detailed clinical systems which will in time reduce reliance on paper records. Local systems will feed a subset of information into both the Summary Care Record and Detailed Care Record systems, and as such will remain the foundation of the records service.[37]

- The **Detailed Care Record** (DCR), which will be created by combining information from local systems and will hold significantly more detailed clinical information than the SCR. It will be created by linking or sharing information from the systems used by local providers (GPs, hospitals, community providers and others) to produce a single, detailed electronic record which can be shared across the local health economy. This means that some patients may have more than one DCR if they have been treated at organisations in different parts of the country. The DCR is likely to contain details of past and current conditions, assessments, diagnoses, treatments and care plans.[38] The systems which will make up the DCR are being provided by LSPs.[39] We look at the DCR in Chapter 4.

- The **Secondary Uses Service** (SUS), which will collect, manage and analyse electronic health data from a range of sources, eventually including the new NCRS systems. The SUS will provide a single point of access to aggregated data for purposes including management, commissioning, clinical audit and research. An early version of the SUS is already in operation, using datasets such as Hospital Episode Statistics to support management functions such as Payment by Results.[40] However, the development of the NCRS will vastly increase the depth and breadth of data available through the SUS by allowing clinical data to be obtained directly from operational EPR systems.[41]

Progress to date

35. The delivery of the NCRS systems relies on the success of a number of related NPfIT projects, particularly the upgrades to network and software infrastructure. For example, the new NCRS systems will be underpinned by a number of national applications including the N3 network, the National Data Spine and the Personal Demographics Service. The DCR can only begin to take shape once the mass upgrades to hospital and community PAS systems have been completed, a task which is proving complex and time-consuming.[42] Similarly, the benefits of the SUS can only be maximised once the other NCRS systems are in place and operating successfully. Although their functions are distinct, the NCRS systems are reliant on each other, and on other NPfIT projects, both for their delivery and for their ultimate usefulness.

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37 Ev 117–118 (HC 422-III)

38 The exact data requirements for the DCR will need to be determined for each clinical specialty and standard datasets will need to be agreed. We discuss this further in Chapter 4.

39 Ev 5–6

40 Ev 8

41 Ev 12

42 Q 35

36. As stated above, the PDS and SUS are now operational, although the range of data available to the SUS remains limited. Following a two-year delay and intervention from a Ministerial Task Force, the SCR is now being piloted at GP practices in the Bolton area, although it is not clear exactly when the system will be made available throughout England. The timetable for delivering the DCR remains unclear, largely because of delays to the new Millennium and Lorenzo hospital PAS systems, as well as the replacement of IDX with Cerner as the main software supplier to the London and Southern clusters. An early version of Cerner's Millennium system has now been deployed at some hospitals, but iSoft's Lorenzo system is yet to be deployed anywhere. Until such basic systems are in place, the development of the shared DCR cannot begin. More detail about progress on the main NCRS systems is provided in Chapters 3, 4 and 5 below.

International comparisons

37. The NCRS is one of a number of EPR systems being implemented across the developed world. During our inquiry, we visited three other countries currently undertaking major EPR projects:

- **Canada**, where efforts to create a Private Lifetime Record for each citizen are being co-ordinated by Canada Health Infoway (CHI). CHI aims to establish an electronic record for 50% of Canadian citizens by the end of 2009;[43]
- **France**, where legislation to create a Dossier Médicale Personnel (DMP) was passed in June 2004. The DMP will contain a range of health information which can be viewed online. Access will be controlled by patients who will legally own their record. The DMP system is being implemented between 2006 and 2010 at an estimated cost of €1.2–1.5 billion;[44] and
- The **United States**, where a number of integrated electronic records systems already exist, for example the VistA system used by the Veterans Affairs Administration. In 2004, President Bush set out the goal of establishing electronic health records for "most" US citizens by 2014.[45]

38. The situation in these three countries is similar in many ways to that in England. In general:

- There are **low rates of IT use** and investment in healthcare compared with other sectors of the economy; indeed, more information about patients is generally stored electronically in England, especially in GPs' surgeries, than in the other countries;
- There are **islands of excellence**. For instance, at the Children's Hospital of the Vanderbilt University Medical Center in Nashville, USA, there is an EPR system for inpatients and outpatients. We saw a number of technologies, including StarChart which allows faster access to patient data such as lab

43 See www.infoway-inforoute.ca/en/home/home.aspx for more details

44 See www.d-m-p.org/

45 See www.govtech.com/gt/91029

results and radiology reports; and WizOrder, a "computer physician order entry system", which can help guide drug dosing for patients and check for allergies.[46] An online portal allows patients to access the results of most tests, and to send messages to their doctor;

- There are plans to introduce a **summary electronic patient record** in Canada and France. In Canada, CHI is overseeing the introduction of the 'Private Lifetime Record', which will include high level information about the patient's medical, medication and immunisation history, including diagnostic information such as X-rays and lab results. The information will be accessible from hospitals, community health centres and GP offices. Eventually, patients will be able to access their information from home.[47] In France, the national DMP will gather data from a range of local systems including hospitals, community providers and pharmacies into a single record. The DMP will include medical notes, images and prescription information and a section for patients to record information;[48] and

- Ensuring **interoperability** and consistent **clinical information standards** are important goals. In Canada, a range of local systems will continue to be used in hospitals and elsewhere, but they must be able to exchange information with the EPR. All information will be stored in coded form using SNOMED CT clinical codes. In France, the success of the DMP depends on organisations having local systems, such as that at Amiens, which can interact with the national system. There is a long way to go with this: for example, only a third of French hospitals have digital imaging systems. In the USA, Regional Health Information Organisations have been established to promote the sharing of information.

39. However, a significant difference between England and these other countries is that existing IT systems are being replaced by new IT systems purchased centrally by Connecting for Health on behalf of hospitals and other local organisations. This is possible largely because the majority of providers in England form part of the NHS. In France and Canada, independent healthcare providers will purchase their own systems which must be interoperable with national systems. In the US, the Certification Commission for Healthcare Information Technology aims to encourage healthcare providers to purchase accredited, interoperable systems.[49]

Conclusions

40. **The National Programme for IT (NPfIT) is a complex and ambitious set of projects intended to transform the use of information technology in the NHS. At the heart of the programme is the NHS Care Records Service (NCRS), which aims to introduce a**

46 For further details, see www.mc.vanderbilt.edu/

47 See www.infoway-inforoute.ca/en/ValueToCanadians/EHR.aspx for more details about the Canadian "Private Lifetime Record"

48 For more information about the DMP, see www.d-m-p.org/demonstrateur/

49 See www.cchit.org/about/

range of electronic patient record (EPR) systems. EPR systems offer significant potential improvements to the safety, quality and efficiency of care and are being implemented in most health systems in the developed world.

41. NPfIT is characterised by a centralised management structure and large-scale procurement from private suppliers. This approach aims to offer improved value for money and to address the previously patchy adoption of IT systems across the health service. The Department defended the progress made by NPfIT to date, arguing that the programme is on course to succeed. However, serious doubts have been raised, from sources including the Public Accounts Committee, about how much has been achieved and about the likely completion date. In particular, progress on the development of the NCRS has been questioned.

42. During our inquiry, both at home and abroad, similar messages were given to us repeatedly from different sources. We commend these to the Department:

- **The EPR is essential and is the top priority for improving health care.**
- **The installation of a comprehensive IT system is a long journey best managed by a staged and piloted development not a big bang approach.**
- **The input of end-users is vital in planning, design and implementation.**
- **Local flexibility is essential to allowing continued use of effective systems already in place, as is interoperability if local systems are to communicate with one another.**
- **As EPR systems make more personal health data accessible to more people, breaches of security and confidentiality must be regarded as serious matters.**
- **The support of the public must be obtained. The fact that EPR systems are essential for the delivery of modern health care and can improve communication between different health care staff and between staff and patients must be adequately publicised to users of the NHS. We believe this would help to convince people of the necessity and benefits of the EPR and reduce resistance where it exists.**

3 The Summary Care Record

Introduction

43. In this chapter we examine the development of the national Summary Care Record (SCR) under the following headings:

- A **description** of the SCR, including the content of the record, the situations in which it will be used and the reasons for developing a national summary record;
- **Progress** on the development of the SCR and the timetable for completing the project;
- Plans for **patient consent systems** for the creation of the SCR record and for adding information to the record; and
- The **security systems** which will be used to ensure that SCR information is held safely, including technical and operational security systems.

Description

General

44. The SCR is intended to provide a summary of key health information, which can potentially be accessed by clinicians anywhere in the country. An SCR will eventually be created for every NHS patient in England, provided they do not choose to opt out of having a record. Unlike the Detailed Care Record (DCR), every patient's SCR can be made accessible in all parts of the NHS to users with the appropriate level of access. Information held in the SCR will be extracted from existing GP records, and later from other sources, and uploaded to and stored on the National Data Spine.

45. The SCR is one of the main Spine applications being developed by BT and works alongside another Spine application, the Personal Demographics Service (PDS). PDS data will be used to determine all of the patients for whom an SCR is to be created and to ensure that duplicate records are not created. Use of the SCR requires NHS organisations to be connected to the Spine via the N3 network.[50]

46. Patients will be able to access their own SCR data on the internet using a website called HealthSpace. HealthSpace will allow patients to view but not alter information, to add their own notes and comments to the SCR record, and to access more detailed background information, for example on diagnoses and treatments.[51]

50 Officials told the Committee that there are now more than 19,000 N3 connections in hospitals, GP surgeries and other facilities across the health service: see Q2.

51 Q 568

Content of the Summary Care Record

Officials' views

47. Determining exactly what information would be held on the new NCRS systems was one of the main aims of the Committee's inquiry. However, the information and explanations which we received from Connecting for Health about the content of the SCR changed markedly during the course of our inquiry. Initially, in its memorandum submitted in March 2007, the Department told us that:

> At first, the Summary Care Record will contain only basic information such as known allergies, known adverse reactions to medications and other substances (e.g., peanuts) acute prescriptions in the past 6 months and repeat prescriptions that are not more than six months beyond their review date...In due course more information will be added about current health conditions and treatment.[52]

48. However, when questioned in detail on 26 April about the content of the SCR, Connecting for Health officials described the content as "customisable at a local level", implying that different information will be placed on the SCR in different parts of the country.[53] Dr Gillian Braunold, National Clinical Lead for GPs at Connecting for Health, stated at the same evidence session that some information from hospital records will be placed on the SCR.[54]

49. Officials provided more detailed and somewhat different information at the evidence session on 14 June. Dr Simon Eccles, National Clinical Lead for Hospital Doctors at Connecting for Health, described three distinct sets of information that could be placed on the SCR:

- Information on allergies, adverse drug reactions and recent prescriptions, described as "life-saving" information, derived from the patient's GP record. This information will be placed on the SCR when it is created;
- More detailed information about basic medical history, key operations and procedures, physiological and lifestyle details, which can subsequently be added to the SCR, again derived from the GP record; and
- Basic details of hospital visits including discharge summaries, outpatient clinic letters and A&E summaries, which can be placed on the SCR from 2008.[55]

Other views

50. Witnesses expressed concerns about the Department's changing descriptions of the content of the SCR. In addition, some argued that the inclusion of more and more data

52 Ev 5
53 Q 6
54 Q 25
55 Q 559

would erode the value of the record as a brief but clinically useful summary.[56] Other witnesses thought that patient consent systems would be undermined by the expansion in the content of the SCR, something we consider in more detail below. Dr Paul Cundy, Chair of the General Practitioners' Committee Joint IT Committee, stated that,

> We are aware that there are already, even before the evaluation of the pilots is completed, suggestions that the Summary Care Record should also collect data from Choose and Book (i.e. referrals data) and also possibly the electronic prescriptions service. So it is already looking like far more than just a summary record.[57]

51. Other witnesses were scathing, particularly about the perceived inconsistency of the information received from Connecting for Health. Joyce Robins of Patient Concern commented that, "the grave impression is that they are making it up on the hoof".[58]

Uses of the Summary Care Record

Officials' views

52. The way in which the SCR will be used depends upon what information is included. It is not surprising, therefore, given the uncertainty about the content of the record, that a number of different uses for the SCR were described to the Committee. Dr Gillian Braunold told the Committee that:

> The Summary Care Record is intended to be a first cut of information to help clinicians who have no access to any other records in the first instance who are unfamiliar with the patient, to help them to get started so they are not working in an absence of information.[59]

53. Officials suggested that the SCR would be of particular value in providing care to the following patient groups:

- patients travelling regularly around England;
- unconscious patients receiving emergency care;
- unscheduled care for frail, elderly patients in the community; and
- patients being treated out of hours.[60]

54. Subsequently, Dr Braunold also described plans to use the SCR to provide continuous care for patients with long-term conditions as well as supporting unscheduled care. She commented that:

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56 See, for example, Q 85

57 Q 80

58 Q 246

59 Q 6

60 Q 4 and Q 7

> ...one of our early adopter PCTs...is planning to use the Summary Care Record to help the people who are looking after patients with diabetes in the community, as well as in hospital and general practice; and they want to ensure that the content of the Summary Care Record will help to manage that care, and will have in it the recent results and the recent visits to the various members of the team.[61]

55. Dr Braunold went on to argue that the SCR could be used to fulfil some of the functions of the DCR while the latter is being developed:

> My personal belief is that the amount of information in the Summary Care Record will start growing bigger and then go smaller again as the Detailed Care Records become the actual way that in the locality people start to share information...[62]

Other views

56. However, other witnesses expressed serious concerns about widening the uses of the SCR in this way, arguing that such practices would undermine both consent systems and security procedures. Dr Martyn Thomas, Professor of Software Engineering at Oxford University, stated:

> The notion that you could introduce a Summary Care Record and then use it as the Local Care Record, because it had the flexibility to enable local care groups to upload whatever information they wanted to and could agree to actually share amongst themselves, looks to me like a specification creep that is highly likely to undermine the security policies that are being put in place...[63]

HealthSpace

57. Officials were at least somewhat clearer about the intended use of the HealthSpace website. Patients will be able to use the site to gain access to their SCR and to look at more detailed, generic information about their conditions and treatments, as well as general health information. Patients will also be able to add their own notes and comments to their HealthSpace record.[64]

The benefits from a summary record

Critical views

58. The evident confusion over the content and likely uses of the SCR led some witnesses to question the value of having separate national SCR and local DCR record systems. One witness described the separate record systems as "an ill-defined fudge".[65] Frank Burns, author of the 1998 *Information for Health* strategy, argued that the introduction of the SCR

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61 Q 6

62 Ibid

63 Q 85

64 Q 568

65 Ev 132

before local DCR systems have been implemented represented "an enormous distortion of priorities".[66] He argued that:

> ...it [the SCR] is of less value clinically and less value to patients than the deployment of clinically rich functional technology supporting doctors and nurses on a day-to-day basis.[67]

59. Dr Paul Cundy thought that the development of two separate records systems represented a departure from NPfIT's original plans which envisaged a single, integrated record, available nationally:

> ...your Committee is recognising the volte-face of the programme, because certainly it was true in 2003, when it was first announced as a national programme, it was going to be a single record accessible to anyone anywhere...We now have a very different description...[68]

Officials' views

60. Officials disagreed, however, arguing that the goals of the NCRS have been consistent since the inception of NPfIT. Richard Granger told the Committee that the development of a separate SCR and DCR:

> ...is not a change of direction; that is the details of plans which were documented in Spring 2002...That document set out very clearly that there needed to be more widely accessible summary information and detailed local information...[69]

61. More importantly, officials stressed the clinical value of the SCR dataset, particularly "life-saving" information about allergies, adverse drug reactions and prescription information.[70] Harry Cayton, National Director for Patients and the Public at the Department of Health, stated:

> ...there seems to be quite a clear consensus, certainly around clinical people, that this small data set...is a significantly useful data set in clinical terms.[71]

62. Richard Granger also pointed out the value of the SCR in supporting local unscheduled care:

> The summary care record is going to be the first port of call for the 115.5 hours a week when the GP practice is shut, so I think it is quite a useful instrument to have regardless of whether you stay in one place or move around...[72]

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66 Ev 142

67 Q 503

68 Q 80

69 Q 3

70 Q 566

71 Q 7

72 Q 577

63. Lord Hunt, then the Minister responsible for the NPfIT programme, stressed the unique value of giving patients access to their SCR record through HealthSpace. He commented:

> ...the great advantage of HealthSpace is...there will be a whole host of information about health, and my own view is that it has huge potential in helping people take control of their own health.[73]

64. However, Dr Paul Thornton, a GP, highlighted the need to protect vulnerable patients from being coerced into giving others access to their SCR through HealthSpace. He warned that:

> Vulnerable patients will find it difficult to resist pressures from "friends", abusive spouses, and parents to access and divulge the contents of their SCR.[74]

Progress and implementation

The early adopter programme

65. The first pilots of the SCR were originally planned for December 2004. However, delivery of the system was postponed following delays to the delivery of the National Data Spine.[75] Consultation about what should be included in the SCR and how the system should be implemented also took longer than originally planned.[76] A Ministerial Task Force was established in July 2006 "to resolve the ethical and practical differences" between different stakeholders including Connecting for Health, NHS bodies, professional organisations and patient groups.[77] The Task Force reported in December 2006 and pilots of the SCR began in Spring 2007, around two years behind schedule.[78] Richard Granger acknowledged that the delivery of the SCR has been delayed by two years because of "a mixture of software complexity and an extended consultation period".[79]

66. The report of the Ministerial Task Force recommended that Connecting for Health should "make haste slowly" with the implementation of the SCR, piloting all of the different functions, including patient access through HealthSpace, in its early adopter sites, and evaluating pilots carefully. The Task Force also recommended more training for staff in the use of the SCR applications and a concerted attempt to improve public understanding of the SCR and its benefits.[80] Following the Task Force report, the SCR system was launched in March 2007 at two PCTs in the Bolton area. The first patient information was uploaded in May 2007 and will be available to out-of-hours service

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73 Q 568

74 Ev 188

75 National Audit Office, *Department of Health: The National Programme for IT in the NHS*, HC 1173, p.4

76 Q 3

77 Report of the Ministerial Taskforce on the NHS Summary Care Record, December 2006, p.4

78 Ev 9

79 Q 3

80 Report of the Ministerial Taskforce on the NHS Summary Care Record, December 2006, pp.9–11

providers from August 2007.[81] Connecting for Health announced in April 2007 that the SCR early adopter programme would be independently evaluated by University College London.[82]

Wider implementation of the SCR

67. It is not clear exactly how long it will take to implement the SCR across England. Connecting for Health has stated that the full roll-out will take "several years" and separately that it will last "up to 2010".[83] The evaluation of the early adopter programme will run until April 2008 and its final report will be published in summer 2008.[84] The Department told us that "the subsequent national roll-out is expected to commence in financial year 2008/9.[85]

68. Despite the delays to the initial implementation of the SCR, officials assured the Committee that the amended timetable will prove reliable. Richard Granger commented that:

> BT have delivered every one of their central software drops on time for the past 18 months. There was lots of delay before that, but this has become quite a reliable delivery environment now.[86]

69. Officials also predicted that there will be genuine enthusiasm amongst clinicians and patients for the SCR system to be rolled out. Dr Braunold stated:

> I have no doubt that the value of a coded record on the summary...will have GPs and patients crying out for the Summary Care Record faster than we can deliver it.[87]

70. Some planned features of the SCR programme are not available at present but will be added later in the early adopter phase. For example, we were told that electronic "sealed envelopes" to allow patients to restrict access to particularly sensitive information are due to be available from April 2008.[88] In addition, patients will be able to access their personal information on the HealthSpace website some point during the early adopter phase.[89]

Consent systems

71. One of the key areas examined during the Committee's inquiry was the degree to which patients will be able to control what information is contained in their SCR and who is able to access it. This has proved a complex and controversial subject with considerable media and public debate surrounding the first trials of the SCR. Witnesses stressed that consent

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81 Ev 147 (HC 422–III), section 11.25

82 Q 31

83 See, for example, www.nhscarerecords.nhs.uk/patients/when-is-this-happening

84 Q 61

85 Ev 147 (HC 422–III), section 11.25

86 Q 69

87 Q 56

88 Q 66

89 Q 23

systems are important and require careful planning and communication if trust in records systems is to be maintained.[90]

Initial plans: an opt-out consent system

72. In its initial submission to the Committee, in March 2007, the Department of Health stated that patients who did not wish to have an SCR created would be able to opt out of the scheme:

> Individuals who have concerns can choose not to have a Summary Care Record created for them. They will be advised to inform their GP of their views and to request that a note be made of their concerns and the choice they have made. The GP practice may ask the patient to sign a form indicating that they understand and accept that it may not be possible for the NHS to provide them with the same care as others...[91]

73. Harry Cayton stated that the opt-out consent approach was in keeping with the recommendations of the Ministerial Task Force on the SCR, of which he was the chair. He described it as "the most practical, ethical and appropriate way forward" and commented that members of the Task Force had agreed unanimously on the opt-out model.[92] Richard Granger argued with conviction that the opt-out approach would strike an appropriate balance between protecting patient privacy and taking advantage of the practical benefits offered by electronic records systems:

> ...some people would like all information to be available everywhere; and then at the other end of the spectrum there are the privacy fascists who would like to dictate that nobody has any information available anywhere. We have been trying to forge a path between those extremities.[93]

Legal objections

74. Some witnesses, however, argued that the opt-out approach could be subject to legal challenges. Press for Change, the UK's largest representative organisation for transsexual people, predicted that:

> The uploading of data without [explicit] patient consent would leave General Practitioners open to prosecution.[94]

75. Douwe Korff, Professor of International Law at London Metropolitan University, told the Committee that the opt-out system would not be compliant with European law,

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90 See, for example, Ev 75

91 Ev 5

92 See Q 59. Membership of the Ministerial Task Force included the BMA, the Royal College of Nursing and the Royal College of GPs.

93 Q 27

94 Ev 87

regardless of whether it met the requirements of the UK Data Protection Act.[95] He concluded that:

> If one uploads the summary care record or the more elaborate care records without making that distinction one is extremely likely to break European law... I would be happy to take a case to the European Court of Human Rights in Strasbourg which has also become increasingly aware of and strict in the support of data protection principles.[96]

76. However, the legality of the opt-out approach proposed by the Department was supported by evidence from the Information Commissioner's Office, the organisation which regulates data privacy.[97] Jonathan Bamford, the Assistant Information Commissioner, told the Committee that:

> If patients are informed that they can exercise a proper choice over what happens to their information on the basis of transparency, and they have the opportunity and time to make that choice, it is consistent with the requirements of the Data Protection Act to provide it on an opt-out basis.[98]

Mr Bamford also argued that the opt-out consent approach was consistent with European legal requirements.[99]

Ethical objections: should an opt-in system be used?

77. Other witnesses argued that the opt-out consent model was unethical and would be likely to reduce patient choice and empowerment. Joyce Robins of Patient Concern stated that:

> We were active in the Department of Health's consent initiative four years ago. Since then we and many other groups have worked very hard to try to give patients the confidence to play an active part in their own healthcare. The care records scheme with its assumed consent policy drives a tank through the whole thing. We are back to the old paternalistic idea "We'll do what's good for you; don't you bother your confused little heads."[100]

78. Andrew Hawker, an NHS patient, commented that even if the number of patients choosing to opt out of the SCR programme proved very low, their wishes should be respected. He regarded Connecting for Health documents describing the risks to patients of not having an SCR as "ominous" and "over the top".[101] Mr Hawker concluded that:

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95 See Q 166. The European legislation referred to by both Professor Korff and Mr Bamford is Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

96 Q 166 and Q 175

97 Ev 71

98 Q 162

99 Q 169

100 Q 177

101 Q 115

> ...we have to come back to whether or not an individual patient has the right to say, "I do not want information handled in a particular way", and I was very disturbed to hear the sort of argument that says 98% of people are going to come round, therefore these other troublesome people should be swept aside.[102]

79. Ethical objections to the opt-out consent model were expressed by clinical as well as patient groups. Amongst those advocating an opt-in or explicit consent approach were the British Medical Association (BMA), the Royal College of Psychiatrists and a number of individual GPs.[103] The BMA stated that:

> ...it is for patients to decide, in discussion with a healthcare professional where appropriate, the extent to which their clinical information is placed on electronic systems...The BMA's policy is for explicit consent to be obtained before any healthcare information is uploaded onto the system.[104]

80. Dr Paul Cundy argued that an opt-in or explicit consent approach would be a more effective way to build patient trust in the new system. He suggested that consent could be gained by GPs during routine consultations:

> When the patient next comes to see their GP you can discuss whether you want something going on [to the SCR], you can do it slowly over time, and in taking that approach, which is a default opt-in approach, you slowly build the system and that allows time for trust in the system to be developed.[105]

81. However, officials expressed clear objections on 26 April to the use of an opt-in consent system. Harry Cayton argued that an informed consent system would be impractical, estimating that "100 years of GP time" would be required to offer informed consent to every patient in the country.[106] He also thought that an opt-in system would tend to disadvantage vulnerable groups:

> ...if you have an informed consent to be part of the system, then large sections of society, particularly some of the most vulnerable people in society, do not take part. They do not take part because they do not know how to give informed consent, they do not take part because they do not understand what is being asked or offered and they do not take part because of physical immobility...[107]

Subsequent plans: a hybrid consent system

82. In spite of these comments, the Department of Health subsequently outlined more detailed consent proposals for the Summary Care Record, which included the addition of a significant opt-in element. A supplementary memorandum, received on 12 June 2007, explained that:

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102 Q 116

103 See Ev 41, Ev 103, Ev 137, Ev 149 and Ev 186, respectively

104 Ev 42

105 Q 118

106 Ibid

107 Q 59

> ...the assumption of implicit consent (i.e. the opt-out approach) relates only to the initial setting-up of the Summary Care Record and the inclusion of medication, allergies and adverse reactions. The next stage of adding the patient's significant medical history will occur only after a discussion between the patient and their GP and therefore requires explicit consent (i.e. opting-in) unless there is a lawful basis for recording information without consent, e.g. when a patient lacks capacity.[108]

83. At the subsequent evidence session on 14 June, Dr Simon Eccles confirmed to the Committee that information will be placed on the SCR in at least three separate phases with different consent models. Dr Eccles explained that:

- The creation of the SCR and the addition of information about allergies, adverse drug reaction and prescriptions will take place by **implied consent** i.e. unless the patient chooses to opt out;
- More detailed information such as significant medical history, key operations and lifestyle information can subsequently be added but only with **explicit consent** from the patient. Patients can view this information before it is added to the SCR; and
- Hospital information such as discharge summaries, clinical letters and A&E summaries can also be added with **explicit consent** from the patient.[109]

84. The Department's 12 June memorandum also provided more details about patients' options for regulating access to the SCR. Three distinct consent positions were described:

- The 'red' position: the patient chooses not to have an SCR created;
- The 'amber' position: the patient chooses to have an SCR created but not accessible to clinicians other than their GP; the patient can subsequently choose to grant access to specific clinicians;
- The 'green' position: the patient chooses to have an SCR created and made accessible to any clinician caring for the patient or with another legitimate interest in viewing the information.[110]

85. It is difficult to assess views amongst clinical and patient groups about the hybrid consent system eventually set out by the Department because the details of the system were only made clear to the Committee at the end of its inquiry. It is clear from the evidence received that most stakeholders believed that the opt-out consent model would apply to all information placed on the SCR. Patients in particular expressed concern about the lack of clarity about both content and consent.[111] Andrew Hawker, an NHS patient, offered an eloquent perspective on the situation:

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108 Ev 120 (HC 422–III)

109 Q 559

110 Ev 120 (HC 422–III)

111 See, for example, Q 196

> I feel like a passenger boarding a plane. On board are technicians arguing about how the plane's controls should be wired together, and who should do it. The plane has not had many test flights, and some of those have crashed. Meanwhile, flight attendants are handing out brochures saying how safe it all is.[112]

86. Yet it is clear that the proposed hybrid consent system will help to address a number of the questions raised by witnesses by giving patients more control over their information and ensuring that more detailed information is only added to the SCR with explicit consent. Concerns that particularly sensitive information, for instance about sexual health, might be added to the SCR against a patient's wishes are to some degree addressed by using an explicit consent model for information about medical history. There are some clear exceptions to this rule, particularly prescription information, which will be added to the SCR with implicit rather than explicit consent. As FIPR pointed out, prescription information will often be sufficient to allow an educated guess of possible diagnoses to be made, a difficulty which is not addressed by the hybrid consent model.[113]

87. Similarly, concerns about large numbers of clinicians having potential access to the SCR are in part addressed by the 'amber' consent position which will allow patients to have an SCR created but not shared without their permission. Given the advantages of the hybrid consent system, it is perplexing that the Department has not done more to make the full details available to patients, clinicians and other stakeholders.

88. Moreover, the new consent system exposes contradictions in the Department's position. Officials have at times contradicted themselves and each other. The use of an 'opt-in' system for the majority of SCR information, for example, ignores the arguments made by Harry Cayton on 26 April that such an approach will disadvantage vulnerable groups.[114] Mr Cayton also argued at the same session that this approach was unsuitable as it would use up very large amounts of GP time.[115] Yet Dr Simon Eccles subsequently argued on 14 June that the impact on GP time is likely to be minimal.[116]

Patient ownership

89. During its visit to France, the Committee learnt that French patients will legally own their Dossier Médicale Personnel (DMP), the equivalent of the SCR. This means that patients can use sophisticated controls to regulate access to the DMP and clinicians cannot access the record unless the patient is present and agrees. French officials argued that this approach had helped both to make the DMP more popular with patients and to safeguard information privacy. The importance of patients having greater ownership of their SCR was stressed during our inquiry by the NHS Alliance and the Royal College of GPs.[117]

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112 Ev 159

113 Ev 63

114 Q 59

115 Ibid

116 Q 571

117 See Ev 79 and Ev 94 respectively

Sealed envelopes

Description and progress

90. Another planned feature of the consent system is the introduction of "sealed envelopes", which will allow patients to restrict access to specific pieces of information which they consider particularly sensitive. Such systems are planned for both the SCR and for local DCRs. The Department explained that two different types of "sealed envelopes will be available to patients:

- The standard "sealed envelope" which is visible to clinicians accessing the patient's record but which can only be opened with specific permission from the patient; and
- "Sealed and locked" envelopes which are not a visible part of the patient's record and whose existence is known only to the patient and clinicians with permission to view the information.

91. "Sealed envelopes" are not yet a functioning part of the SCR system and are not available to patients in the first early adopter sites. However, officials told the Committee that this functionality would be available by April or May 2008.[118] This date was confirmed by BT, the suppliers of the SCR system.[119] However, it was not clear when DCR "sealed envelopes" would be available.[120]

92. The Committee heard during its visit to Paris that controls similar to "sealed envelopes" (and known as "masquage" systems) will be available to protect information in the Dossier Médicale Personnel. French officials told us that "masquage" systems have already been completed.

Questions and concerns

93. Unsurprisingly, witnesses expressed concern that the software to create "sealed envelopes" has not been completed before the start of the SCR early adopter phase. Dr Peter Gooderham, a GP, complained that:

> ..."sealed envelopes" have been advanced as an important method of protecting patient confidentiality. However, the technology was not in existence at the time the Department of Health described them... This appears highly unsatisfactory.[121]

Professor Douwe Korff commented that:

> I would not buy a car if the engineer told me he was still working on the brakes but by the time I was a few miles away he would probably have sorted it out.[122]

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118 Q 68

119 Q 486

120 See Qq 301–305

121 Ev 153

122 Q 218

94. Questions were also raised about how effective "sealed envelopes" would be at protecting confidentiality. The Assistant Information Commissioner told the Committee that his organisation was concerned about whether sealed information could be accessed in an emergency and whether patients would be able to see audit trails showing who had accessed this information.[123]

95. However, officials defended the efficacy of the planned systems. Dr Gillian Braunold told the Committee that "sealed envelope" systems had been demonstrated to a conference of sexual health clinicians, a group which she described as "the most challenging...of all that exist" and "the most sceptical" about plans for protecting sensitive information. Dr Braunold explained that exactly half of this group expressed positive support for the NCRS in light of planned consent arrangements.[124]

96. Other witnesses expressed concern that information in "sealed envelopes" would be made available for research and other purposes via the Secondary Uses Service. Professor Douwe Korff argued that particularly sensitive information should not be accessible in this way, even following anonymisation or pseudonymisation, as this would breach European law.[125] The Department of Health subsequently clarified that while "sealed" information will be available to the Secondary Uses Service, "sealed and locked" information will not.[126] We consider these issues further in Chapter 5.

Security systems

97. Witnesses also expressed concerns about whether SCR data, and other information held on the National Data Spine, could be held securely. These concerns fell into two broad categories which we consider below:

- One set of concerns related to the **technical security** of the national systems, for example the likelihood of the system being infiltrated by hackers and the possibility of data theft from the SCR; and
    - Separate concerns were raised about operational security, also referred to as the "human factor"; such concerns focussed on how access to the SCR would be controlled and monitored, particularly across an organisation as large, complex and federated as the NHS.

Technical security

98. The SCR is one element of the National Data Spine supplied by BT. Access to the SCR is via the New National Network for the NHS (N3), also supplied by BT.[127] The Committee does not have sufficient technical knowledge to make specific judgements on the external

123 Q 221

124 See Q 67. Dr Braunold described a survey in which members of the Sexual Health Conference were asked whether they would support their local service making use of NCRS systems, on the basis of consent systems which included the "sealed envelope". On a scale from 1 (not at all) to 5 (very much), exactly 50% responded with either 4 or 5.

125 Q 218

126 Ev 120 (HC 422–III)

127 The combined value of the contracts for the National Spine and the N3 network is £1.15 billion.

security of these systems and the likelihood of illegal infiltration, nor did we seek detailed, technical evidence about security systems. However, the Committee did seek the general views of officials, suppliers and academic experts about the likely effectiveness of security systems.

Planned security measures

99. Officials acknowledged that no system of information storage can be considered entirely secure and stated that "different vulnerabilities" affect paper and electronic storage systems.[128] Richard Granger pointed out that security risks are being mitigated by the use of experienced suppliers who also work for the security services, by introducing functionality incrementally with thorough evaluation, and by ensuring compliance with HL7 international infrastructure standards.[129] Mr Granger also argued that the significant benefits of sharing information electronically outweigh the small but unavoidable risk of a security breach.[130] In a subsequent submission, the Department described the system's technical security apparatus in more detail:

> The new systems will be protected by state of the art security measures capable of providing far greater protection than has ever been the case previously. The NHS patient database (the Spine) will reside within a fully private network known as N3. The Spine system and database can be accessed only from within this private network. Should an attacker somehow gain access to the NHS private network they would then have to break through three separate layers of tiered architecture—each tier being protected by twin firewalls (of different manufacture) to access the database. The firewalls are supported by intrusion detection systems and other multiple security measures, which monitor network traffic routinely and raise an alert on the detection of suspicious activity.[131]

100. BT, the supplier of the national systems, offered strong assurances about technical security levels, arguing that unlawful access to the National Data Spine would be "near impossible" without the assistance of a registered user, i.e. without a breach of operational security.[132] Patrick O'Connell, Managing Director of BT Health, told the Committee that BT has an ongoing programme of internal testing to ensure that systems cannot be infiltrated.[133] BT also stressed the inevitability of a trade-off between the level of system security and the practicalities of making systems user-friendly, particularly to busy clinicians:

> ...the specification of the system we are delivering achieves an important balance between value for money, operational effectiveness and ease of use, likely threat of

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128 Q 28

129 See Q 31 and Q 34

130 Q 29

131 Ev 120–121 (HC 422–III)

132 Ev 49

133 Q 498

> infiltration and potential for damage through infiltration. Spine has not yet been penetrated.[134]

Challenges and criticisms

101. Some witnesses, however, raised doubts about planned technical security systems. Brian Randell, Professor of Computing Science at Newcastle University, told the Committee that suppliers had not provided information about likely security levels to Connecting for Health:

> When I and colleagues met Mr Granger a year ago we were absolutely shocked to find that Connecting for Health did not have any documents stating things like the reliability and security guarantees. They said that they did not have them because they were regarded as confidential to the suppliers. I still find that absolutely gob-smacking.[135]

102. In its 16 July memorandum, however, the Department stated that:

> Professor Randell was not told that NHS Connecting for Health did not have reliability and security documentation. He was told that this existed but that, for reasons of confidential and commercially sensitive content, they could not be disclosed to third parties…[136]

103. More worryingly, doubts were raised about the overall architecture of the electronic records systems and the decision to create a National Spine for storing and transferring information. Witnesses argued that the creation of a nationally accessible system, rather than a series of smaller, local systems, would increase the risk of security breaches. The UK Computing Research Council stated that:

> …a single system accessible by all NHS employees from all trusts maximises rather than minimises the risk of a security breach. It increases the number of patients affected by the worst case breach…In short, it provides both a bigger target and a larger number of points of attack than a series of smaller systems.[137]

104. The British Computer Society took this point further, arguing that higher levels of security would be achieved by storing information in a "distributed database" rather than on centralised storage systems. Such a system would allow clinicians to search a range of local databases for information about a particular patient which could be drawn together into a "virtual" record when required, rather than being permanently stored in one place.[138] But officials were dismissive of this idea. Richard Granger pointed out that:

> We did not want to, frankly, experiment with the very, very large distributed network. None of the leading suppliers of solutions in this space who are willing to

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134 Ev 49

135 See Q 316

136 Ev 147 (HC 422–III), section 6.32

137 Ev 125

138 Ev 38

bid and take financial and completion risk around the delivery came up with that architecture...[139]

Operational security

105. Many witnesses stated that ensuring the operational security of the new electronic patient record systems is likely to represent a still stiffer challenge than maintaining technical security. This argument was applied particularly to the SCR system, which can in theory give access to clinical information about any NHS patient from any point in the country. The Medical Protection Society commented that security problems are most likely to be caused by "the human factor which is not subject to system controls".[140] BT pointed out that the "nature of the environment" in the NHS would make ensuring operational security difficult, for example because NHS buildings are freely accessible to the public and IT security is unlikely to be closely monitored in busy hospital departments.[141] The challenge was summarised by Symantec:

> ...technology alone cannot be relied upon when developing and implementing electronic patient records. Education and training of NHS staff, at all levels, on the importance of data management will also be required.[142]

Planned security measures

106. Evidence from officials and suppliers described a range of measures which will be used to maximise the operational security of the SCR system. Many of these measures will also be used to protect local DCR systems and some are discussed further in Chapter 4. The measures set out include:

- Access to the SCR system requires users to insert a valid **smartcard** as well as entering a user name and password;
- Receipt of a smartcard follows a **registration** process which requires users to present identification and to be sponsored by a senior member of their organisation (this process ensures that security complies with level 3 of the e-Government Interoperability Framework);[143]
- Users accessing the SCR system will only be able to view information relevant to their job role, so an administrator will not typically be able to view clinical information. This safeguard is known as **role-based access control**;
- Users can only access information about a patient after specifying a **legitimate relationship** with the patient, for example a clinician providing treatment or a receptionist recording the patient's arrival in clinic;

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139 Q 32

140 Ev 78

141 Ev 49

142 Ev 118

143 See Q 28. More details about the e-GIF standards can be found at www.govtalk.gov.uk/schemasstandards/egif.asp

- A full **audit trail** will be maintained by the SCR system, indicating who has accessed patient information and for what purpose. This information can be viewed by GPs and Caldicott Guardians and will be available to patients on request;[144] and
- Attempts are being made to improve the **enforcement** of operational security systems by increasing the penalty for attempting to access information unlawfully. Support for stronger penalties has been expressed by the Information Commissioner's Office, the Department of Health and the General Medical Council.[145]

107. BT also described some technical features of the SCR system which aim to improve operational security, including automatic logouts if systems are left unused and programmes for detecting unusual or malicious accessing of SCR data.[146]

Challenges and criticisms

108. A number of doubts were raised about plans for maintaining the operational security of the SCR system. Professor Brian Randell was sceptical about how effective role-based limitations on access would prove:

> If one has role-based access control with a very large number of complicated roles in a situation where there is a lot of changing roles it will be extremely difficult to deal with all the individual decisions that are being made as to who should have what role and what privileges...I am deeply suspicious of the practical efficacy of such a system.[147]

109. A number of witnesses raised concerns about the use of smartcards to access electronic records systems, and particularly about whether access would be fast enough.[148] However, such concerns did not relate specifically to the SCR system and so we consider them further in Chapter 4.

110. Regarding audit trails, Professor Brian Randell argued that monitoring access to the SCR was a good idea in principle but that the sheer volume of records created would make effective oversight difficult:

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144 More detail about operational security controls can be found at Ev 7 and Ev 121 (HC 422–III). Caldicott Guardians are responsible for internal protocols governing the protection and use of patients-identifiable information by the staff of each NHS, ensuring compliance with national guidance, policy and law.

145 See Ev 6. See also Joint guidance on use of IT equipment and access to patient data from The Department of Health, the General Medical Council and the Office of the Information Commissioner, 25 April 2007, which concludes that "...the law is to be changed to provide the possibility of a custodial sentence for those found guilty [of obtaining information unlawfully]."

146 Ev 50

147 Q 286

148 See, for example, Q 141

> If...one has a system where it turns out that there are huge numbers of audit records being generated to the point where nobody is looking at them, that is a...system that is not being properly designed.[149]

111. Dr Martyn Thomas argued that security systems did not appear to have been designed with users in mind, meaning that people would inevitably "work around" security procedures. He stated that:

> ...in deciding what the specification for the technology should be, you actually need to start by looking at the specification for the overall social system and deriving the specification for the technology out of the way that people are genuinely going to behave when faced with the technology... The moment it appears to them that the systems are getting in the way of them doing their job, which they see as treating patients and running the hospital effectively, they start working around the systems.[150]

112. But suppliers disagreed, arguing that every effort had been made to ensure that security systems did not interfere unnecessarily with existing working practices. Guy Hains of CSC stated that suppliers were "super-sensitive" to the need to design systems which were both secure and practical to use.[151]

Conclusions and recommendations

113. **The Committee is pleased that trials of the national Summary Care Record (SCR) are now going ahead following delays to the project. The SCR has the potential to improve the safety and efficiency of care and to make the health service more patient-centred. The SCR has the potential to improve the safety and efficiency of care especially in emergency situations when care is delivered by staff unfamiliar with the patient involved. The Committee supports the aim of introducing a nationally available summary record as soon as possible and deplores the delays and continuing indecision about its content.**

114. **The SCR has less comprehensive clinical value than shared Detailed Care Record (DCR) systems and is a comparatively straightforward application which extracts information from existing GP systems, whereas DCR systems must be built up from a range of complex and interdependent component applications. Given that there is expected to be clinical value from the SCR, its roll-out should not be held back by delays to DCR systems.** We examine DCR systems in more detail in Chapter 4.

115. **The Committee was dismayed, however, by the lack of clarity about what information will be included in the SCR and what the record will be used for. Officials gave different answers to these questions on different occasions. The Committee was told at various times that the SCR will be used for the delivery of unscheduled care, for the care of patients with long-term conditions, and to exchange information between**

149 Q 300

150 Q 151

151 Q 292

primary and secondary care. It is little wonder that patient groups expressed confusion about the purpose and content of the SCR.

116. The Committee is aware of the Department's most recent plans but is concerned that the complexity of the SCR appears to be increasing. This will make the SCR more difficult to use, particularly in emergency situations. The Department must be clear about the purpose of the SCR, and it must ensure that the record is easy to use. To this end, we recommend that the SCR include a single standardised front screen to display key health information which is vital for emergency care.

117. The Committee has also received inconsistent information about the patient consent arrangements for the SCR. Initially, we were told that information will be added to the SCR with "implied consent", provided patients do not opt out. This approach was strongly criticised by clinical and patient groups. However, it subsequently became clear that while the creation of the SCR, and the addition of "life-saving" details such as prescription information, will require "implied consent", the addition of detailed clinical information will only take place with "explicit consent" from the patient. This hybrid consent system represents a much more satisfactory model but one which has not been well communicated to patients or clinicians.

118. The inclusion of prescription information on the SCR with only "implied consent" remains problematic, however. On the one hand, prescription information can often make a patient's diagnosis obvious. On the other hand, excluding some prescription information from the SCR would be clinically dangerous. If the Department of Health does use the "implicit consent" model for prescription information, it should make clear to patients the implications both for data privacy and clinical safety.

119. The Committee considers that much of the controversy over privacy and consent arrangements for the SCR would have been avoided if Connecting for Health had communicated its plans more clearly to patients. We recommend that Connecting for Health:

- **Make clear to patients, clinicians and the public that detailed information will only be added to the SCR with explicit patient consent, that patients can see this information before it is added, and that patients can choose to have an SCR created but not accessed beyond their GP surgery; and**
- **Offer the same assurances to all patients in the SCR early adopter sites.**

120. The arrangements for the SCR will be strengthened when "sealed envelopes" are made available to protect sensitive information and when patients can access their record via the HealthSpace website. It is unfortunate that these elements of the SCR are not yet in place, but the Committee understands and supports the decision to press ahead in any case with trials of the SCR. Connecting for Health must ensure that both "sealed envelopes" and HealthSpace are introduced as soon as possible, particularly so that their effectiveness can be assessed during the independent evaluation of the early adopter programme.

121. "Sealed envelopes" are a vital mechanism if sensitive information is to be held on the SCR. We recommend that:

- The right to break the seal protecting information in "sealed envelopes" should only be held by patients themselves, except where there is a legal requirement to override this measure; and

- Information in "sealed envelopes" should not be made available to the Secondary Uses Service under any circumstances; this will allow patients to prevent data being used for research purposes without their consent.

122. HealthSpace is an excellent addition to the SCR programme and has huge potential to improve the safety and efficiency of care by allowing patients to check the accuracy of their SCR and to access detailed information about their own health. In order to take fuller advantage of HealthSpace, we recommend that Connecting for Health:

- Trial the use of HealthSpace for patients, particularly those with long-term conditions, to record their own measurements of key health information;

- Ensure that HealthSpace allows patients to view audit trails, showing who has accessed their SCR record and under what circumstances, and offers mechanisms for investigating inappropriate access;

- Promote the use of HealthSpace, monitor levels of uptake, and ensure that there is equitable access across the country and that coercive access is prevented; and

- Commission an independent evaluation of HealthSpace once the system is widely available.

123. We note that in France patients will own their national summary record. This approach gives patients more control over who can access their record and more opportunity to influence and take control of their own care. We therefore recommend that Connecting for Health consider a similar model for the SCR in England.

124. The Committee does not have the knowledge or expertise to make specific judgements about the likely effectiveness of planned technical security systems at protecting the SCR from external attack. We received strong assurances from officials and suppliers about the quality of security systems, and we accept the inevitability of a trade-off between levels of security and the need to ensure that systems are user-friendly. We also acknowledge that no information storage system can be considered 100% secure.

125. However, serious concerns were expressed regarding the lack of information both about how security systems will work and about the outcomes of security testing. We agree with these concerns and recommend that Connecting for Health ensure that BT's planned security systems for its national applications are subject to independent evaluation and that the outcomes of this are made public.

126. Maintaining the operational security of the new SCR system is a substantial challenge. We acknowledge that Connecting for Health and its suppliers have made significant efforts to minimise the risk of operational security breaches. Individual smartcards, rigorous user authentication, role-based access controls, legitimate relationships and audit trails will all help to increase operational security, both

individually and in combination. However, many of these measures are new and untested on the scale that they will be used in the NHS. As a result, their impact and vulnerabilities are difficult to predict. We therefore recommend that Connecting for Health:

- **Ensure that the evaluation of the early adopter sites examines both the individual and the collective impact of the new operational security measures for the SCR, commissioning a separate evaluation if necessary; and**
- **Undertake a program of operational security training for all staff with access to the SCR, emphasising the importance of not divulging information to those who request it under false pretexts.**

127. **Operational security also depends on effective enforcement. The Department of Health and the Information Commissioner's Office have called for custodial sentences for people who unlawfully access personal information. The Committee welcomes this, and recommends that a substantial audit resource be provided to detect and prosecute those who access the system unlawfully.**

4 Detailed Care Records

128. As well as the national Summary Care Record, the NHS Care Records Service aims to create more detailed patient records at local level and the capacity to share rich clinical information between local organisations. In this chapter we examine the development of local Detailed Care Records (DCRs) and the systems which will support them. We look particularly at:

- The different visions of how local electronic records systems will work, including significant areas of uncertainty, as well as the substantial benefits of introducing shared local systems;
- Progress to date on the delivery of the various components of local electronic record systems and the timetable for the completion of shared DCR systems;
- Arguments about the way forward on the development of DCR systems; and
- Issues relating to the safety and reliability of DCR systems and the model for patient consent.

Vision and potential benefits

129. The creation of DCR systems represents a large and complex set of projects and accounts for the bulk of expenditure on the NCRS.[152] One official described DCR systems as the "Holy Grail" of the national programme.[153] In this section we look at how DCR systems will work and their great potential to improve patient care. We focus in particular on:

- The overall vision for shared DCR systems;
- The benefits offered by DCR systems;
- The various component systems which will contribute to the shared record and the infrastructure developments required to support the DCR; and
- Outstanding areas of uncertainty about exactly what will be provided.

Overall vision

130. NPfIT's original vision for creating shared local records systems was set out in its specification document for the "Integrated Care Records Service", published in 2003. The document described the need for "integrated clinical information systems across the whole care continuum" and envisaged that "the patient will pass seamlessly through the system with...information flowing with the patient". Integrated local record systems were

152 Expenditure on contracts for the 5 LSPs represented around 80% of the initial £6.2 billion spending on NPfIT. Regional LSPs will deliver the majority of systems which make up the DCR as well as the shared record itself.

153 Q 10

described as "the foundation and bed-rock for integrated care".[154] Integrated records systems would support "care pathways", examples of which included a routine GP visit, a hospital referral to fit a pacemaker, and the A&E admission of a diabetic suffering a hypoglycaemic attack.[155] Electronic systems to support these "care pathways" were to be delivered in basic form by December 2006 and in full by 2010.[156]

131. However, the Department's descriptions during our inquiry of local record systems, now referred to as "Detailed Care Records" (DCRs), bore little resemblance to this blueprint, and did not make reference to the 2003 specifications.[157] Nor was it clear whether DCRs are still intended to support the integrated "care pathways" set out in 2003. There was a stark contrast between the specific and detailed vision set out for the "Integrated Care Records Service" in 2003, and the vague and shifting vision set out for the DCR in 2007.

132. During out inquiry, the Department did provide general, high-level descriptions of how DCR systems will work. We were told that the broad aim of the DCR project was to standardise the information collected from a range of local records systems, including hospital and GP records and imaging databases, and from these create an integrated record. Hospitals, GP surgeries and other provider organisations would continue to have local records systems, and not all the information held locally would be available on the DCR. However, local systems would need to be able to communicate with each other and to exchange data to create the integrated DCR. The exact information contained in the DCR, and the size of the area covered by each DCR network, would be likely to vary across the country, and would also depend on the specific clinical requirements for managing the patient.[158]

133. The Department's 12 June 2007 memorandum described existing local storage systems where patient information is generally kept on a range of different records which often overlap and are very rarely linked together. A single patient may have:

- A GP record, "usually held electronically but often supplemented by paper records";
- An electronic hospital record with administrative and demographic details at each hospital the patient has visited;
- Separate paper records containing clinical information at each hospital visited;
- Further separate records for maternity care, mental health care, sexual health care, and for each separate A&E attendance;[159] and
- Records of care received in the community, for example for long-term conditions.

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154 National Programme for Information Technology, *Output Based Specification Version Two, Integration Care Records Service"* Part II – LSP Services, 1 August 2003, p.4.

155 Ibid, Introduction, pp.44–45.

156 Ibid, Part II – LSP Services, pp.72–3

157 See Ev 5-6 and Ev 117 (HC 422–III)

158 Ev 117 (HC 422–III)

159 Ibid

134. The Department described the ultimate goal of the DCR project as to bring information from these separate records systems together to create a shared electronic record accessible across the local area. The Department stated that:

> The Programme [NPfIT] has a clear objective to reduce this duplication of diverse records by providing a patient centred electronic Detailed Care Record that spans these areas. As a minimum, this would be within a hospital but there are real benefits when providing a consistent record across a local health community and across the boundaries involved in care pathways for a patient.[160]

135. Other witnesses described the potential of the DCR project to enable communication between distinct organisations, as well as providing shared records. Fundamental to this communication is the ability of separate IT systems to exchange information, a concept known as "interoperability". Dr Paul Cundy highlighted the importance of ensuring that systems are compatible:

> You want the electronic island of hospital to be able to communicate a meaningful message about a patient to the electronic island that is relevant (e.g. the general practice)...and that is precisely what interoperability is about and I believe that is precisely what you are seeing the programme now moving towards.[161]

136. DCR systems can also change the way that care is delivered by supporting clinical processes and decision-making, and allowing activities such as prescribing to be done electronically. Frank Burns described more sophisticated DCR systems as "patient care management systems" rather than merely patient records systems.[162] Alan Shackman, an IT consultant, commented on the great potential for changing clinical processes by introducing DCR systems. He stated that:

> The summary care record is basically an information repository...but a detailed care record is much more than that... The key thing is that the detailed care record more than a database allows clinicians and others to do things. It allows them to prescribe drugs, to order tests. It allows care plans to be devolved. It allows quite complicated things to be done...[163]

Benefits from Detailed Care Record systems

The Department's view

137. Witnesses consistently emphasised the benefits of providing shared local electronic records. The Department of Health's March 2007 memorandum set out a range of advantages, including:

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160 Ev 117 (HC 422–III)

161 Q 102

162 Q 500

163 Q 413

- **Increasing efficiency** by ensuring that relevant information can be shared more quickly and the same information is not collected and recorded on multiple occasions;
- Underpinning the provision of **integrated care** between different organisations, between primary and secondary care, and even between different parts of the same organisation. This will offer particular benefits for the growing number of patients with long-term conditions;[164] and
- **Reducing medical errors**, by providing more accurate and timely clinical information and, for example, through the provision of electronic prescribing services.[165]

Other views

138. Other witnesses agreed that DCR systems have great potential to increase the integration of care, and particularly to improve care for patients with chronic and long-term conditions.[166] The Renal Association stated that:

> ...the great majority of health gain from NHS CRS will be in *local* health communities. The largest early gains will be in the care of people with chronic disease.[167]

139. Frank Burns argued that the greatest benefits will derive from sophisticated clinical systems which not only record and share information but also automate clinical processes such as prescribing. He stated that:

> ...these systems actually support practising clinicians in their day-to-day work providing better care for patients; and where clinical management systems have been installed...there is very serious evidence of the capacity of these systems to improve patient care... The real priority for the NHS...in my view, and I think it is a view that is supported by most clinicians, is for detailed care records at a local level.[168]

140. Others agreed that the benefits gained from implementing local DCR systems were significantly greater than those from the national SCR system. The Association of the British Pharmaceutical Industry wrote that:

> ...increasing patient safety through the active monitoring of safety and efficacy of new and existing medicines...cannot be achieved without access to the detailed electronic patient record. This will not be provided by Connecting for Health in the proposed centrally-held Summary Care Record.[169]

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164 See Ev 2–4

165 More detail about the potential impact of DCR systems on patient safety was provided in the Department's 16 July memorandum. See Ev 147 (HC 422–III), section 15.1.

166 Ev 143

167 Ev 92

168 Q 500

169 Ev 17

141. Most witnesses confirmed that DCR systems would offer a substantial range of significant benefits. The very strong case for their introduction was summarised by Frank Burns:

> Having to make the case for [local] electronic records is on a par with having to make the case for the telephone, the television, central heating and the motor car.[170]

Infrastructure and components for the Detailed Care Record

142. Achieving the ultimate vision for the DCR, and the many benefits which it offers, relies on the success of a large number of complex projects. These include upgrades both to the infrastructure supporting IT across the NHS and to large numbers of local IT systems in hospital, community facilities and GP surgeries. In order to achieve the level of system interoperability necessary to support effective DCR systems, Connecting for Health has set out to replace significant elements of existing NHS IT systems.

A national foundation

143. A fundamental part of the infrastructure for the proposed DCR systems is the New National Network for the NHS (N3), provided by BT under a national contract. N3 connects all NHS organisations in a private network and will be the vehicle for all sharing of information between separate IT systems. The secure communication necessary for DCR systems to share information safely and efficiently relies heavily on N3.[171]

Local building blocks

144. Responsibility for implementing DCR systems falls largely to the Local Service Providers (LSPs) operating within each of the five regional "clusters". LSPs are responsible both for the upgrading of large numbers of local IT systems, and for ensuring the interoperability between systems required to support the DCR. The main projects being undertaken by LSPs are set out below:

a) The **replacement of hospital Patient Administration System (PAS) software** is a vital step in creating DCRs. All hospitals will receive new PASs which have the capacity to communicate both with national NPfIT systems, such as the Spine, and with other local systems, for example GP systems. All patient data on existing PAS systems will be transferred to the new systems. Two different PAS products are being installed. In the London and Southern clusters, the **Millennium** system (supplied by the US company Cerner) will be provided.[172] In the remaining 3 clusters, a new product called **Lorenzo** (developed by iSoft, a UK firm) is to be introduced.[173] As well as replacing administrative functions, the new PAS applications will offer some clinical functions: it is intended, for example, to use the Millennium system to support electronic prescribing.

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170 Ev 142

171 More detail on N3 is provided in Chapter 2.

172 Q 400

173 Q 256

b) The introduction of new PAS systems for **community and mental health providers**, the majority of which previously relied on paper systems, is another key step. Again, new community PAS systems will be interoperable with national and local systems. In the London cluster, the **RiO** system (supplied by CSE Servelec) will be provided for community and mental health care organisations.[174] In the remaining four clusters, the community PAS system will be the same product as the hospital PAS system.

c) The replacement or upgrade of some **GP practice IT systems** was also planned, in particular to ensure that all practices had software which is interoperable with national and local NPfIT systems. Connecting for Health has now decided instead to allow each practice to choose a new or upgraded system from a range of different packages accredited by NPfIT. In order to be accredited, such systems much be fully interoperable with other NPfIT systems. This initiative is known as GP Systems of Choice.[175]

d) LSPs will also install **Picture Archiving and Communications Systems** (PACS) in all hospitals. PACS systems allow X-rays and other images to be captured, stored and shared electronically and will be one of the components of shared DCR systems.[176]

e) Local systems will be further enhanced through the provision of **more sophisticated clinical systems**, particularly in hospitals. Such systems are intended to build where necessary on the functionality provided by new PAS systems, offering more detailed patient record storage as well as more automation of clinical processes. Such systems are typically specific to individual hospital departments, such as cardiology, or to specific patient groups, such as renal patients.[177] We discuss such systems in more detail in the box below.

145. Connecting for Health has chosen to create the DCR by replacing or upgrading a wide range of stand-alone IT systems and ensuring that all such systems are interoperable both with each other and with the national NPfIT infrastructure.[178] The collation of information from these systems to form a shared care record is the ultimate goal of the DCR project.

What do we mean by "sophisticated clinical systems"?

In hospitals, a clinical information system is typically a computerised medical record that provides the usual functions of the patient's paper record. It enables the recording of clinical data generated at times of patient-professional interaction and the presentation of such data at subsequent contacts. Clinical data include problems, symptoms, signs, diagnoses, severity scales, patient expectations, plans, medication,

174 Q 373

175 Q 36

176 See Q 20. The provision of PACS systems did not form part of the initial 2002 NPfIT contracts but was subsequently added to LSP contracts.

177 See Q 520 and Q 556

178 See Q 419. Some witnesses argued that this is different, and inferior, to the approach in other countries where the main goal has been to ensure interoperability at a local, but not necessarily a national, level. The Foundation for Information Policy Research, for example, concluded (Ev 64) that "The NHS has a long, sad history of failed attempts at autarky in IT".

interventions and outcomes.

More sophisticated clinical information systems also support clinical actions such as test ordering, scheduling of investigations and procedures, prescribing and communication. Details may be recorded at contacts (such as ward rounds. consultations or telephone calls), or to document clinical interventions (such as counselling, physiotherapy, angiography, or surgery). Some information will be recorded in structured, coded form, and some as free text.

To date, clinical information systems have typically been designed to focus on the care of patients with defined diagnoses (e.g. diabetes), or to support specific interventions (such as prescribing, operations, endoscopy) or the work of individual departments (e.g. cardiology or urology). However, such systems do not create a comprehensive record for patients with chronic disease or multiple problems, particularly when such patients are seen by many different clinicians. To meet this requirement, still more sophisticated systems are needed, which focus on the individual patient irrespective of the context in which they are seen, and record and support all their problems and care in a single longitudinal record.

A common language

146. Sharing information between different organisations and care settings will require more standardisation and coding of data. This is vital if complex clinical information is to be exchanged accurately and efficiently between a range of practitioners. Efforts to increase the standardisation of clinical information have been co-ordinated by Connecting for Health and include:

- Agreement on the introduction of the Systemised Nomenclature of Medicine, also known as **SNOMED CT**, across the NHS.[179] SNOMED CT is a single comprehensive database of codes covering diseases, operations, treatments, drugs and a number of other areas. It is described by Connecting for Health as "the language of the NHS Care Records Service";[180]

- The development of an **NHS Data Dictionary** so that the meaning of different clinical and administrative terms in the context of the NHS is understood consistently;[181] and

- Attempts to increase the use of the **NHS number** as a unique identifier for patient information. This is vital to developing integrated records as it allows patient episodes which take place in different hospitals, or different departments of the same hospital, to be linked together.[182] Connecting for Health introduced the NHS

179 Q 10

180 See www.connectingforhealth.nhs.uk/systemsandservices/data/snomed

181 For more details, see www.datadictionary.nhs.uk

182 See Q 550 for examples of the problems caused by inconsistent use of the NHS number

> Numbers For Babies scheme, which allocates a lifetime NHS number at birth, in 2002.[183]

We discuss the requirements for standardising information to support DCR systems in more detail below.

Areas of uncertainty

Appearance and content of the DCR

147. In spite of the obvious scale and ambition of the DCR project, the Committee received uncertain and sometimes conflicting evidence about what Connecting for Health and its suppliers will actually deliver. Most fundamentally, it was not clear what the shared DCR will be able to do and exactly what information it will contain.

148. Officials offered some information on this point. Dr Gillian Braunold explained that the DCR will enable information sharing between primary and secondary care, replacing slower paper-based communication.[184] Dr Simon Eccles commented on the importance of ensuring that the new systems installed in GP practices, hospitals and community care organisations are interoperable.[185] But officials did not supply precise details about the appearance or specification of shared DCR systems.

149. Explanations from suppliers were similarly opaque. Patrick O'Connell of BT, the LSP for London, described the DCR as "a single view so that a patient's record can be viewed in a variety of care pathways". Guy Hains of CSC, LSP for three of the five regional clusters, stated that:

> The Detailed Care Record is variously at the GP and a secondary care setting like a hospital where your treatment record will be held.[186]

150. Professor Naomi Fulop of King's College London, whose research has examined the delivery of NPfIT systems in the acute sector, succinctly captured concerns about the lack of detailed information on the DCR:

> What I would add about the detailed record is that it has not been communicated to people what it is.[187]

Depth of information sharing

151. In light of this problem, witnesses inevitably raised other questions about the specific plans for DCR systems. Dr Paul Thornton, a GP, questioned the level of detail of information sharing that DCR systems would offer, concluding that:

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183 See www.connectingforhealth.nhs.uk/systemsandservices/nhsnumber/nn4b

184 Q 10

185 Q 608

186 Q 259

187 Q 416

> Detailed Care Records...can never provide the level of detailed data sharing which would be necessary for shared care.[188]

152. Suppliers provided little reassurance, commenting that the degree to which local organisations store and share information electronically will in part be for them to decide. Guy Hains of CSC stated that:

> University Hospital Birmingham has an advanced view; it wants to move to a very high level of electronically-stored records. Other hospitals may choose also to have a reference to paper-held records. We are not mandating the level of efficiency and automation to which those hospitals take their full records.[189]

153. Neither suppliers nor officials made clear whether organisations would be subject to specific requirements for sharing information through DCR systems. Witnesses argued that it is therefore difficult to assess the level of detail which DCR systems will provide and to judge the clinical value of the planned records.[190]

Breadth of information sharing

154. A related set of concerns focussed on the range of organisations and the geographical area which will be covered by each DCR. Professor Naomi Fulop and Dr Paul Thornton both highlighted fears that organisations which are geographically adjacent may be unable to share information, because they form part either of different health economies or of different NPfIT clusters. Such barriers, they argued, would inevitably reduce the value of the shared DCR.[191]

155. Suppliers stated that the scope of information sharing would be decided locally. Guy Hains compared plans for two different areas:

> ...one would be Morecambe Bay Acute Trust where there are 2,500 users effectively on one system compared with Greater Manchester...They have a system for Greater Manchester with about 13,500 users on it.[192]

156. The Department of Health told us that there is likely to be significant variation regarding the breadth of the area across which DCR systems will be shared. The Department's 12 June 2007 memorandum stated that:

> ...in future, records can be shared amongst a locally determined health community that is on the same IT system. Typically, as a minimum, this is at GP practice level or hospital level but can span Strategic Health Authorities (SHAs) or other local health communities as agreed between the NHS and suppliers.[193]

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188 Ev 189–190

189 Q 266

190 See, for example, Ev 177

191 See Ev 136 (HC 422-III) and Ev 189–190 respectively

192 Q 280

193 Ev 118 (HC 422–III)

Sophistication of new systems

157. Some witnesses also questioned whether the new administrative and clinical systems due to be supplied as components of the DCR would represent significant improvements on existing systems. The Renal Association, for example, commented that:

> Many renal centres have well-developed decision support systems that should not be lost by the introduction of generic less flexible systems. It is unclear whether the proposed Lorenzo solution will be able to offer the same level of sophistication on which we have come to rely.[194]

158. Frank Burns argued that the upgrading of hospital PAS software would not represent a significant advance in itself, as such systems have been in used in hospitals "for the last 20 years".[195] He pointed out that significant advances will not be possible until more complex clinical systems are installed, a development for which there is no clear timetable.[196] Mr Burns also commented that:

> Many in the NHS believe that by the time the systems procured are implemented...what they end up with will not be the sophisticated clinical management systems that they need for modern healthcare.[197]

We provide more detail on what is meant by "sophisticated" clinical systems in the box above.

Progress and implementation

159. Although many questions were raised about precisely what DCR systems comprise, these were significantly outnumbered by concerns about when such systems would be delivered. In this section, therefore, we look at the progress to date on implementing the various components of local record systems and the shared DCR itself. We look particularly at:

- Progress in developing each of the **specific systems and components** which will make up the DCR;
- The **timetable** for the completion of the shared DCR itself;
- **Reasons for delays** to elements of the DCR project and to the provision of shared local records;
- Progress on the delivery of new **hospital PAS software**; and
- Progress on developing coding systems, a unique identifier and **clinical information standards** to enable data sharing.

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194 Ev 90

195 Q 515

196 Ibid

197 Ev 144

Progress on specific systems

160. Progress to date on each of the main systems which will contribute to the shared DCR is set out below:

a) The **N3 Network and National Data Spine**, which provide the backbone for all sharing of information between systems, are both operating successfully. Officials told us that more than 19,000 N3 connections have been installed across the NHS and that the system had been completed two months ahead of schedule.[198] Functions are being added to the National Spine incrementally following earlier delays of around ten months to software delivery.[199] With regard to the N3 network, Richard Granger stated that "we have one of the biggest virtual private networks on the planet and people take that for granted."[200]

b) By contrast, the delivery of **hospital PAS systems** has been significantly delayed. The Department acknowledged that implementation is "up to two years behind the original schedule".[201] Because of the importance and complexity of this element of the DCR project, we examine it in specific detail below.

c) The delivery of **community and mental health PAS software** has apparently been more successful than that of hospital systems. Officials told us that 105 systems have been deployed in total.[202] Patrick O'Connell stated that BT has made 18 deployments of the RiO systems to community providers in London.[203] CSC stated that 60 community PAS deployments have been made across its three clusters.[204] But Alan Shackman argued that the community software deployed by CSC represented an interim solution that will have to be replaced once again when the Lorenzo product becomes available.[205]

d) Connecting for Health procured a catalogue of accredited **GP systems** in February 2007 under the GP Systems of Choice initiative, which we discuss further below. Connecting for Health has also put in place a system for transferring records between GP practices, known as GP2GP.[206]

e) **Picture Archiving and Communication Systems** (PACS) have been successfully implemented in three-quarters of hospitals, according to the Royal College of Radiologists.[207] Several witnesses argued that, because of the maturity of PACS technology and the enthusiasm for implementing these systems, such success would

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198 See Ev 10 and Q 45 respectively

199 National Audit Office, *Department of Health: The National Programme for IT in the NHS*, HC 1173, p.4

200 Q 2

201 Ev 9

202 Q 581

203 Q 373

204 Q 253 and EPR 46A (unpublished)

205 Ev 178–9

206 See Ev 9. Dr Paul Cundy argued (Q 96) that provision of the GP2GP system was a requirement of the 2003 GMS contract and not a specific achievement of NPfIT.

207 Q 551

have been achieved irrespective of NPfIT.[208] However, the Department disagreed, pointing out that the speed with which PACS applications have been delivered has increased dramatically as a result of the national programme.[209]

f) The delivery of **Electronic Transfer of Prescription** (ETP), also known as electronic prescribing systems, has been less successful, particularly in hospitals. Officials told us that while use of ETP systems is growing in GP and community settings, use in the acute sector is limited to a "handful" of hospitals.[210] Richard Granger told the Committee that hospital ETP systems will be introduced "over the next two to three years".[211] In *Delivering 21st Century IT*, published in 2002, the Department set a target for 100% coverage of ETP systems in the NHS by the end of 2007.[212]

g) The delivery of other more **detailed clinical systems** has been very limited, largely because of the delays in implementing basic hospital PAS applications. Although such systems are not a prerequisite of shared DCR systems, more clinically rich systems will add significant value to the DCR.[213] The Lorenzo and Millennium systems are likely to offer some clinical functions, but Connecting for Health also put out a tender earlier this year for a range of other clinical systems. We discuss this in more detail below.

h) Due to the delays to a number of constituent projects, progress on the delivery of **shared Detailed Care Records** has hardly begun, as we set out below.

Delivery of the Detailed Care Record itself

Officials' views

161. The Department did not provide an exact timetable for achieving the ultimate goal of the DCR project, the delivery of the shared record itself. Its initial submission in March 2007 stated that:

> The transformation from paper to digital information will take place gradually up to 2010 and beyond.[214]

162. The subsequent memorandum, received in June 2007, argued that specific completion dates could not be given because of the wide range of systems being delivered across different parts of the country and different tiers of care. The Department also pointed out that DCR systems will be built up incrementally and as such do not necessarily have a fixed implementation or completion date. The Department concluded that:

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208 See Q 512 and Q 96. Frank Burns stated (Q 512) that "It would be almost impossible not to achieve a rapid roll-out of PACS given central funding."

209 Ev 10

210 See Qq 621–627

211 See Q 623. The Department provided more details regarding plans for electronic prescribing systems in its 16 July memorandum—see Ev 147 (HC 422-III), sections 9.1–9.4.

212 Department of Health, *Delivering 21st Century IT support for the NHS: national strategic programme*, June 2002, p.6

213 Q 503

214 Ev 11

> ...it is not a single monolithic system due for delivery or go-live at one point in time. The Programme comprises a range of new and existing systems, introduced incrementally and meeting the Programme's objectives over time...LSPs' plans are all based on delivering incremental improvements.[215]

163. Officials also challenged the view that the delivery of DCR systems as a whole is behind schedule, arguing that each element of the new systems should be considered separately. Richard Granger stated that:

> It is inaccurate to state that the whole of the programme is late. That is not true. Some of the programme is late, some of it is on time and some of it is early...[216]

Suppliers' views

164. BT, the LSP for the London cluster, provided a clear timetable for the completion of DCR systems within this area. In its written evidence, the company stated:

> The foundations of the NPfIT system provided by BT are now built, operating and secure. Culturally integrating these systems so they become second nature for NHS staff is well underway. Over the next five years, the goal is to complete this programme.[217]

165. In oral evidence, Patrick O'Connell set out a still shorter timetable for the completion of DCR systems in London:

> ...this year and next year [i.e. 2007 and 2008] we are rolling out the basic stand-alone capability...once it is established that we have the capability then we intend to link it together...In a stand-alone capability we should finish in 2009 and complete and integrated in about 2010.[218]

Thus, according to Mr O'Connell, all London hospitals, community providers and GP surgeries will have had their basic systems upgraded by 2009 and integration of systems to create the DCR system will take place in 2010. However, as discussed above, the exact content of the DCR, and the degree of information sharing that will initially be possible, were not made clear.

166. CSC, the LSP for three of the five NPfIT clusters, did not provide such a precise timetable for the introduction of DCR systems. Guy Hains told the Committee that the Lorenzo system, intended to be the main PAS software for hospitals and community providers, would be implemented for the first time "in the middle of next year", suggesting an overall timetable some way behind that of BT.[219] Fujitsu, the LSP for the Southern cluster, did not provide evidence to the Committee.

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215 Ev 122 (HC 422–III)

216 Q 37

217 Ev 47

218 Q 439 and Q 375

219 See Q 256—we discuss the introduction of hospital PAS systems later in this chapter.

Other views

167. Other witnesses were more sceptical about when DCR systems would be delivered. The British Association for Community Child Health described detailed shared records as "a mirage with an ever receding completion date".[220] Alan Shackman pointed out the continuing delays to the introduction of hospital PAS applications have meant that more sophisticated clinical systems cannot be deployed. He concluded:

> ...there remains no definitive timescale for introducing the clinically focused software that would take functionality in any significant way beyond the basic PAS functionality that was available to the NHS when NPfIT began in 2002.[221]

168. Frank Burns also commented that more "clinically rich" systems, from which the greatest benefits will be derived, have proved the "slowest in coming forward".[222] Mr Burns gave the specific example of acute trust electronic prescribing systems, one of the original objectives of the NPfIT project and an important component of DCR systems. He stated that:

> As far as the hospital side is concerned, electronic prescribing is the very last in the list of things that are going to be delivered by NPfIT, and there are people who fear they will never ever be delivered.[223]

169. In short, witnesses argued that even if some form of shared DCR systems were delivered in the next few years, more clinically rich systems will take much longer to provide.[224] In this context, the current lack of clarity about content and levels of information sharing within DCR systems is worrying, especially when compared with the 2003 specification documents which provided a lot of specific detail about the project's original goals.[225] Dr Martyn Thomas expressed grave concern about the loss of clarity about what the project will deliver and changes to the "milestones" for demonstrating step-by-step progress on the development of the DCR. He argued:

> What typically happens is that people start redefining what the milestones meant, in order to claim success for milestones and to put off the day when they have to admit that things have gone wrong, and they start arguing about what it was they really were setting out to do at the beginning, so they start getting a bit weasely about what the specification really was...[226]

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220 Ev 35

221 Ev 177

222 Q 503 and Q 501 respectively

223 Q 544

224 Q 501

225 See National Programme for Information Technology, *Output Based Specification Version Two, Integrated Care Records Service*, 1 August 2003

226 Q 159

General causes of delay

170. It is clear that some elements of DCR systems, such as the N3 network and hospital PACS, have been delivered on time. Yet others, such as hospital PAS and ETP systems, have fallen significantly behind schedule, leading to overall delays in the delivery of shared records themselves. A very wide range of reasons was suggested for the delays to these elements of the project, as we set out below.

Officials' views

171. Officials offered several explanations for the delays to DCR systems:

a) Significant **expansion to the scope of the project** had been a cause of delays. This included the addition of a number of projects, for example PACS, QMAS and GP2GP transfer, to the overall scope of NPfIT. Richard Granger acknowledged that the addition of new systems had set back the implementation of DCR systems, but argued that "in the real world it would be ridiculous to imagine that halfway through a ten-year programme you would only be doing the same things as you set out five years ago".[227]

b) This problem was compounded by the **fixed budget** for the project. Officials argued that development problems could not be resolved by spending extra money, for example on temporary staff, and that some time delays were therefore inevitable when difficulties were encountered. Mr Granger told us that "the only expression of dealing with problems on this programme is necessarily time, because we are operating within a financial cap and the functionality demands have tended to increase rather than decrease".[228]

c) The implementation of new systems, particularly where this involved a **replacement of existing systems**, proved more difficult that envisaged.[229] We discuss this with particular reference to new hospital PAS deployments below.

Suppliers views

172. Suppliers offered somewhat different, though not conflicting, explanations for delays. Patrick O'Connell of BT argued that NPfIT "is following a profile that is somewhat typical of very large national transformation programmes".[230] He went on to state:

> I have been managing these things for about 24 years now...Typically, they do have a slow start but with the right spirit and the right expertise on both sides they get around the corner and they start to perform...I think you will see us picking up speed as we go along.[231]

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227 Q 46

228 Q 75

229 Q 35

230 Q 372

231 Ibid

173. CSC argued that the sheer scale and complexity of the programme had led to delays. The company stated that "the deployment of technology across an organisation as complex and far reaching as the NHS" represented a unique undertaking, making it difficult to provide accurate timetables for completion. CSC also described the original timetables for the programme as "ambitious".[232]

Other views

174. Other witnesses offered a wide range of explanations for delays to DCR projects. The most commonly suggested were:

- **Unrealistic and overambitious timescales** for delivering new systems.[233] Stalis, a UK technology firm, stated that "project goals must be realistic and those for NPfIT in general and the Care Records Service in particular were not".[234]
- A **lack of clear specifications** for what the programme would deliver. Dr Martyn Thomas argued that without such specifications "any schedule that you put together…is built on sand".[235]
- A failure to appreciate the need for **changes to processes and working practices** to accompany the installation of new systems. Witnesses argued that this had meant organisations were often unprepared to receive new systems or unwilling to volunteer for implementations.[236]
- The **excessively centralised approach** adopted by the programme, not only to procurement but also to the delivery of new systems. Witnesses argued that this approach had stifled local activity, for example on implementing hospital PAS software, and left individual organisations frustrated and disengaged.[237] Professor John Feehally of the Renal Association commented that: "if at the beginning of this sorry process they had simply given local health networks some resource and said, 'You will just simply resolve the question of the primary care computer system talking to the hospital computer system', we would all now be smiling".[238]
- A **lack of clinical and user engagement** in the development of new systems which has made it difficult to stimulate progress and activity at a local level.[239] The BMA argued that increased clinical engagement "could have highlighted potential problems at an earlier stage" and thereby reduced overall delays.[240]

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232 Ev 52

233 See, for example, Ev 99

234 Ev 116

235 Q 106

236 For example, Professor Naomi Fulop (Q 422) criticised the lack of focus on "socio-cultural issues and change management issues in implementing these systems."

237 See, for example, Ev 84 and Ev 45

238 Q 507

239 See, for example, Ev 82 and Ev 39

240 Ev 45

Upgrading hospital Patient Administration System software

175. The delays to the delivery of new hospital PAS software were highlighted as a particular cause for concern. These delays have had the knock-on effect of delaying the deployment of more sophisticated clinical systems in secondary care. Such systems are a core element of the DCR: shared records cannot be achieved without properly functional and integrated electronic hospital records.

Progress and timetables

176. Progress on implementing new PAS systems has varied across the different regional clusters, as we detail below.

a) BT plans to install Cerner's Millennium PAS software at hospitals across **London**. Patrick O'Connell told the Committee on 7 June that BT planned to complete all local deployments by 2009 but that only one deployment has taken place to date, at Queen Mary's hospital in Sidcup.[241] The Millennium system has also been deployed at Homerton and Newham hospitals as part of a local procurement with no connection to NPfIT. BT had originally planned to use IDX as its hospital PAS supplier but switched to Cerner's Millennium system in July 2006.

b) Cerner's Millennium system will also be deployed by Fujitsu at hospitals in the **Southern** cluster. Like BT, Fujitsu had planned to use IDX as its supplier but switched to Cerner in June 2005. Fujitsu and BT had worked together on a "Common Solution Project" for installing hospital systems across their clusters, but this partnership was also dissolved in 2005.[242] Alan Shackman stated in March 2007 that the Millennium system had been deployed at five acute trusts in the Southern cluster. He commented that after "a false start", progress on deployments was "encouraging".[243]

c) In the **North East, Eastern and North West & West Midlands** clusters, CSC plans to deploy iSoft's Lorenzo software in all hospitals. Unlike Cerner's Millennium system, which is already widely used in the US, Lorenzo is a new-build application.[244] There have been no deployments of Lorenzo to date and none are planned until mid-2008, according to CSC.[245] Richard Granger told us that Lorenzo would be trialled in Germany in June 2007 but confirmed that no deployments in England would take place until 2008.[246] Guy Hains commented that CSC was putting "an awful lot of support" into developing the product.[247] CSC has made 11 deployments of a more limited PAS application, iPM, at hospitals in the North West & West Midlands cluster.[248] However,

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241 See Qq 373–375

242 Patrick O'Connell of BT described the "Common Solution Project" (Q 376) as "...a well-intentioned idea that should work at the macro level but did not work at the practical level because it turns out that the differences were more than seemed reasonable at the time."

243 Ev 179

244 Q 57

245 Q 256

246 Q 572

247 Q 256

248 EPR 46A, unpublished

> Alan Shackman described iPM as a system "with no clinical functionality" which could not contribute to a shared DCR system.[249]

Reasons for delays to hospital PAS implementation

177. Differing explanations were given for the delays to the two main hospital PAS applications, Millennium and Lorenzo. Although some deployments of Cerner's **Millennium** system have now taken place, implementation is still behind schedule. Richard Granger commented that one cause of the delays had been difficulties in "anglicising" Millennium, which is primarily used in the US, so that it could operate in the NHS.[250] Patrick O'Connell commented that switching software suppliers from IDX to Cerner had delayed hospital PAS deployments in London.[251] Mr O'Connell also cited the breakdown of the "Common Solution Project" between Fujitsu and BT as a cause of delays.[252]

178. Regarding the **Lorenzo** system, Richard Granger stated the sheer complexity of building a new software system from scratch had delayed the project.[253] Guy Hains of CSC commented that the need for rigorous testing and the decision to make Lorenzo an internationally available product had both contributed to delays.[254] Mr Hains also acknowledged that takeover speculation regarding iSoft, the company developing Lorenzo, had added to the problem, commenting that "uncertainty regarding iSoft and its future ownership has proved an unwelcome distraction".[255]

179. Richard Granger also pointed out that the process of actually deploying new hospital PAS software had proved more difficult than expected, particularly because of the need to move data from old systems onto new ones without causing excessive disruption to the delivery of care. He stated that:

> Brownfield site implementations are incredibly difficult…You might have half a million records…that have to be cleaned up by staff in the hospital…It is a big heavy-lifting systems engineering job. It is like replacing the core systems in a small government department or small corporation…in a weekend.[256]

Impact of delays

180. Hospital PAS applications are a fundamental element of DCR systems and delays to their deployment have been a primary cause of difficulties in making progress on the provision of shared records systems. Witnesses also pointed out other problems caused by delays in upgrading hospital systems, including:

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249 Ev 178

250 Q 57

251 Q 378

252 Q 376

253 Q 57

254 Q 256

255 Ibid

256 Q 35

- A possible impact on **patient safety** in hospitals with particularly old computer systems, because of reliability problems and difficulties in maintaining out-of-date software.[257] One witness described a trust buying new parts for its PAS from eBay because they were no longer available elsewhere;[258] and

- **Frustration and disengagement** at local level because of continuing delays, and particularly because the delays to new PASs prevent more clinically rich systems from being deployed.[259]

Coding and information standards

181. So that information can be accurately shared and combined between the different parts of the DCR system, data will increasingly need to be recorded in a standard way. The Department of Health described the need for "a much more structured approach" to record keeping, stating that:

> ...clinicians will need to adopt the new approach to record keeping. This will need a cultural change in the practices of health professionals which should not and could not be led by an IT programme but must be seen as a significant improvement to patient care and therefore owned and led by the NHS.[260]

The NHS number

182. Witnesses highlighted the importance of the unique identifier, the NHS number, in increasing the standardisation and quality of a patient's record. Professor Carol Dezateux of the Institute of Child Health described the 2002 introduction of NHS Numbers for Babies, which allocates a lifetime NHS number at birth, as "an outstanding success".[261] But Dr Mark Walport of the Wellcome Trust pointed out that the NHS number is not yet regularly used for all patients whenever they come into contact with the NHS.[262] Professor Dezateux argued that the NHS number should be used whenever a patient interacts with the health service. She commented:

> There is not a mandated system for doing that but it is not technically challenging or difficult to do, given the right leadership and the right go-ahead.[263]

183. The difficulties caused when a unique identifier is not used were outlined by Dr Gill Markham of the Royal College of Radiologists. She described the inconsistent use of the

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257 Q 382

258 Q 385

259 See Q 385 and Q 501

260 See Ev 118–119 (HC 422–III). The continuing need for some information in free text was also acknowledged by the Department.

261 Q 338

262 Q 339

263 Q 338

NHS number as a "huge difficulty", giving the example of problems with the sharing of diagnostic images.[264] She commented that:

> ...largely because of this [inconsistent use of the] unique identifier, you cannot transfer images; and there is an enormous industry at the moment with people burning CDs, putting the images onto CDs that then get sent to the hospital that might be two miles down the road...[265]

184. Dr Markham and Professor Dezateux both pointed out that consistent use of the NHS number has been achieved in Scotland, which has a separate numbering system. They argued that this should be a key priority for the NHS in England and that effective use of a unique identifier would significantly improve the quality of clinical information, benefiting both direct patient care and clinical research.[266] In its 16 July memorandum, the Department of Health told us that plans are in place to achieve more comprehensive usage of the NHS number, but did not set a specific timetable for achieving this:

> Work underway currently with the authority of the National Programme Board is aiming to ensure that the NHS number is mandated by the Information Standards Board and subsequently adopted incrementally for use within IT systems across the NHS within a reasonable period.[267]

185. Dr Markham also highlighted the need to allocate temporary NHS numbers rapidly, for use for example when patients are admitted unconscious for emergency treatment, but added that these temporary numbers should be subsequently reconciled with the unique permanent NHS number.[268]

Coding systems

186. As mentioned above, significant progress on introducing a single coding vocabulary into the NHS has already been achieved. Connecting for Health has been active in the development of SNOMED CT, an internationally recognised coding system for recording clinical data including symptoms, diagnoses, treatments, drugs and a range of other information.[269] SNOMED CT will be used to code data in both SCR and DCR systems. The importance of using a common coding system across the NHS was highlighted by Dr Paul Cundy. He explained that:

> Exchanging or sharing data between systems that have disparate coding arrangements creates unnecessary complexity and introduces dangers. It is accepted

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264 Q 522

265 See Q 550. In its 16 July memorandum, however, the Department of Health argued that the inability to share images generally results from "the legacy of locally-commissioned systems that are not interoperable" rather than the lack of a unique identifier.

266 See Q 556 and Q 338 respectively. We discuss the use of the NHS number to support clinical research in more detail in Chapter 5.

267 Ev 147 (HC 422–III), section 5.26

268 Q 524

269 Q 10

that all systems in the NHS should use a common coding system and one has been identified; SNOMED.[270]

Clinical information standards

187. However, witnesses argued that there was also a need for a more holistic approach to standardising information for use in DCR systems. The Royal College of Physicians (RCP) pointed out that alongside a universal coding system there is a need for agreed datasets and approaches to structuring information. Such "information standards" will allow information to be shared meaningfully between clinicians, reduce the potential for errors, and make it easier to use data for health research. The RCP argued that significant work was required to agree information standards for different clinical specialties (e.g. cardiology and gastroenterology), different disease areas (e.g. diabetes and epilepsy) and different care settings (e.g. outpatients, admissions and GP consultations).[271] Coding, in short, offers a common *vocabulary*, but exchanging detailed clinical information also requires an agreed *syntax*, which is likely to vary between different clinical specialties and patient groups.[272]

188. Unfortunately, there was little evidence of progress in this important area. The RCP stated that:

> The definition of this detail and the structure of the record to record it should be agreed nationally, based on work undertaken by appropriate professional bodies such as the Royal Colleges and Specialist Societies. To date the Colleges have not been requested to undertake this work...[273]

189. When questioned about plans for this work, officials argued that Connecting for Health has had regular contact with Royal Colleges and other specialist societies.[274] Lord Hunt also told us that a new forum would be established at national level between Connecting for Health and the Academy of Medical Royal Colleges.[275] But officials did not explain the purpose of such engagement and did not set out plans or progress on developing the necessary professionally-agreed information standards.[276]

Changing working practices

190. Central agreement on new ways of coding, structuring and recording clinical information is of little value if such systems are not used at a local level. Officials

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270 Ev 130 (HC 422–III)

271 See Ev 100–101

272 The RCP gave the example of work to develop a standard approach to collecting and recording information about acute medical admissions. It commented (Ev 101) that "The Royal College of Physicians has developed both generic medical record-keeping standards and standards for the structure and content of the acute medical admission."

273 See Ev 101, the RCP pointed out that it has pioneered work on information standards for the acute medical admission, but this had not been done in conjunction with Connecting for Health.

274 Q 610

275 Q 580

276 By contrast, the Committee heard on its visit to Canada that developing detailed clinical information standards had been one of the earliest priorities for Canada Health Infoway, the organisation responsible for developing EPR systems.

commented that the implementation of clinical coding systems at the front line was likely to prove challenging, especially in secondary care. Richard Granger stated that:

> It is going to be a long and difficult process to get the complexities of secondary care to code information in a way that it can be used outside of the location in which it was originally created.[277]

191. Mr Granger also commented that difficulties had been encountered when implementing Cerner's Millennium system at hospitals in the Southern cluster because of the need to code more information at the point of care.[278] But officials did not say how they planned to address such problems on a wider scale. Nor was it made clear what support will be given to hospitals and other organisations to change working practices. Alan Shackman underlined the lack of focus on changing clinical processes:

> ...the change management, changing the process...was going to be covered by the Modernisation Agency, which no longer is with us, so I struggle a bit to find any concerted way of helping make the process change happen whereas of course there is a most concerted way of actually getting the technology in.[279]

The way forward

192. It is clear that some elements of the DCR programme, such as the creation of the N3 network and the roll-out of hospital PACS systems, are set to be successfully achieved. However, it is equally evident that other parts of the project are beset by significant problems. The most serious of these are:

- The lack of clarity about the ultimate vision for the shared DCR record, particularly the area which will be covered and the level of information which will be shared;
- The absence of a clear timetable for implementing shared DCR records; and
- Ongoing delays to the delivery of new hospital PAS software, a key prerequisite for implementing both shared record systems and more sophisticated local hospital EPR systems. The failure to deploy the Lorenzo system anywhere in the NHS is a particular concern.

193. Witnesses made a range of suggestions for addressing these complex challenges and for ensuring that the delivery of DCR systems is achieved as quickly and effectively as possible. The most common proposals, which we discuss below, were:

- An **independent technical review** of the programme, examining plans, progress and requirements for successful delivery; and
- A concerted effort to increase **local ownership** of the programme, in particular by devolving responsibility for the delivery of DCR systems.

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277 Q 10

278 Ibid

279 See Q 422. The Modernisation Agency was closed in 2004.

An independent technical review?

194. Amongst those witnesses to call for an independent technical review of the programme were the UK Computing Research Council and Computer Weekly magazine,[280] but the clearest explanation of the case for a review came in a submission from a group of 23 "senior academics in computing and systems".[281] The 23 academics drew on a "Dossier of Concerns" submitted to the Committee in 2006, which detailed a litany of problems with the programme.[282] These concerns, totalling 35 in all, ranged from poor planning, an over-centralised approach and unrealistic timescales and budgets, through to "inappropriate aggression and machismo" and "fear of failure".[283] The submission concluded that:

> ...our analysis illustrates very dramatically the number, variety and complexity of the concerns surrounding NPfIT, and thus provides a compelling argument for commissioning a detailed review of the project, carried out by evidently-independent experts with full access to all relevant information and personnel.[284]

195. The case for an independent review was put to the Committee in more detail by Professors Martyn Thomas and Brian Randell, both members of the group of 23 academics. Professor Randell pointed out that public IT programmes have benefited from such reviews in the past and stressed that the review should look at operational as well as technical aspects of the programme.[285] Professor Thomas gave the example of the new Swanwick air traffic control system, which he argued had benefited significantly from an external review.[286] He also argued that a review by external experts would be able to resolve issues which the programme's leaders might be unaware of or unwilling to acknowledge:

> ...my experience of carrying out those reviews is that people get blinded by the fact that they are too close to the project and they get compromised by the fact that they cannot stand back and admit errors.[287]

196. Officials and suppliers both denied the need for an independent, external review. Richard Granger argued that the programme had already been heavily scrutinised, for example by the National Audit Office, and that Ministers had therefore concluded that a further review was not necessary.[288] Guy Hains pointed out that suppliers were subject to regular reviews, both technical and commercial, and stated that elements of the programme were in effect reviewed every two months.[289] Guy Hains and Patrick O'Connell

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280 See Ev 125 and Ev 55 respectively

281 Ev 164

282 See www.editthis.info/nhs_it_info/Main_Page for more details.

283 For full details, see Ev 166–167

284 Ev 167

285 Q 329

286 See Q 132. Professor Thomas also provided detailed written evidence regarding reviews of major IT programmes—see Ev 124–126 (HC 422–III).

287 Q 159

288 Q 74

289 Q 330

both pointed out that individual systems were subject to high levels of audit and testing.[290] Mr Granger was particularly dismissive of the "Dossier of Concerns" prepared by the 23 academics:

> If there are people who want to work from an evidence base, the door has always been open for them to come and work with us, but people who just lob cold collations of negative media coverage in so-called dossiers hardly do themselves a service as a serious group of people that are working from a robust evidence base.[291]

197. Andrew Hawker suggested that rather than undertaking a full-scale review, elements of the programme should be subject to more independent testing with published outcomes.[292] Professor Thomas argued that if this approach were chosen then such testing should focus not only on the technical security of new systems, but also on how DCR systems would actually be used once implemented. He stated that:

> ...my instinct would be to do lots of prototyping and work with the clinicians in the frontline to really find out what works for them, what they are happy with, what works with their patients, and then to stand back and decide what you want to do on a national basis...[293]

Increasing local ownership

198. Some of the strongest criticism of the approach adopted by NPfIT to developing DCR systems argued that procurement and implementation have been too centralised, stifling local ownership and innovation.[294] The need to maintain a balance between central and local input into the programme was acknowledged by officials. Richard Granger commented:

> ...you come back to this paradox of the necessity of strong local leadership and management ownership...with a necessity of buying things at a higher level in the NHS in order to make them affordable. So we have to do both; it is not an either/or...there has to be a balance struck between standardisation and localisation...[295]

The need for central input

199. Officials strongly defended the value of the central direction and leadership which have characterised the programme to date, highlighting in particular that:

- Centrally procured and managed contracts have helped to ensure that widespread upgrades to local systems are **affordable**. Richard Granger argued that where EPR systems have been purchased locally, these have not proved affordable in the long

290 See Q 280 and Q 498 respectively

291 Q 75

292 Q 160

293 Q 90

294 See, for example, Q 507

295 See Qq 583–587

term.[296] He commented that "it is not about all the money being spent nationally. It is about the unit cost being too high if things are bought locally".[297]

- The national approach is necessary to ensure the **consistent development** of new systems across the country, rather than the previous "islands of excellence".[298] Lord Hunt argued that: "the national approach that we have taken was absolutely essential in terms of ring-fencing the resource, giving it the priority and ensuring that the NHS did move in step."[299]

- Central input has a particular role in ensuring **interoperability** between newly procured systems, a fundamental part of establishing shared DCR systems. Richard Granger argued: "if we would like to indulge ourselves with 200 rich local systems across the NHS we not only cannot afford them, we will forever be locked into information not being moveable between locations..."[300]

The need for local input

200. Officials and other witnesses also pointed out the clear advantages of involving local organisations, particularly in the development of the systems which will make up the shared DCR record. The following arguments in particular were put forward:

- The involvement of local users, particularly clinicians, is vital if **implementation of new systems** is to be successful. Lord Hunt pointed out: "it has got to make sense for senior management to engage the clinicians because if you have an institution where the clinicians have not been involved the one thing you can be sure is that when the PAS system is introduced it is not going to work very well".[301]

- Ensuring **interoperability** between systems is best done at a local level and would have been treated as a higher priority if the programme had not been centrally managed. In particular, PCTs should have been given responsibility for ensuring interoperability between local systems.[302]

- **PCTs** are responsible for commissioning healthcare in general and should therefore be made accountable for implementing the DCR, as shared record systems are fundamental to the delivery of care. Frank Burns made the case for more PCT involvement with the programme, arguing that "there needs to be some local accountability for ensuring that patients have reliable records".[303]

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296 See Q578. Mr Granger gave the example of local EPR procurements in the Wirral, Blackburn and Bradford.

297 Ibid

298 Q 577

299 Ibid

300 Q 587

301 See Q 615. The importance of local clinical involvement in implementing new hospital PAS applications was highlighted during the Committee's visit to Homerton hospital.

302 See Q 556, Q 507 and Q 527

303 Q 527

Shifting the balance of power: steps to date

201. There is some recent evidence of changes to the approach to delivering DCR systems in light of the case for increased local input. There are three main examples:

a) The **NPfIT Local Ownership Programme** (NLOP), which was implemented following a review of the management of NPfIT in October 2006. NLOP devolves responsibility for implementing local systems, and for some elements of the management of LSP contracts, from Connecting for Health to the 10 regional SHAs.[304] SHAs were made formally accountable for "implementation and the realisation of benefits" from the programme from 1 April 2007.[305] Lord Hunt stated that implementing NPfIT has been made one of the four key priorities for SHAs.[306] Richard Granger commented that senior staff at SHA level have already become closely involved in the running of the programme and "dealing day-to-day with key contractual management issues in collaboration with Connecting for Health people and frontline staff from trusts".[307]

b) **GP Systems of Choice** (GPSoC), which will allow GP practices to choose their software supplier for new or upgraded practice systems to support the DCR. Suppliers will be approved by Connecting for Health, and will be required to meet interoperability standards, but individual practices can then choose from a number of accredited software systems.[308] GPSoC was launched in March 2006 and procurement of approved suppliers began in February 2007.[309]

c) The procurement of a range of **additional systems** through a tendering process begun by Connecting for Health in March 2007. This procurement is separate from the main LSP contracts and covers a wide variety of clinical and administrative systems with the potential to support the delivery and increase the sophistication of local DCR systems.[310] Additional systems procured in this way must be interoperable with all other NPfIT systems.

202. Witnesses were generally supportive of these efforts. Professor Naomi Fulop argued that NLOP might help to address the problem of users feeling "at the bottom of the food chain", but asserted that it must be "more than a token gesture".[311] Patrick O'Connell commented that NLOP would help to speed up deployments in London, although he did not explain how.[312] Dr Paul Cundy expressed support for providing a choice of suppliers for GPs, although he pointed out that this was actually a requirement of the 2003 GMS

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304 See Q 583. SHAs will be given individual targets for completing deployments.

305 See EV 147 (HC 422–III) , section 16.2.

306 Q 580

307 Q 605

308 Q 36

309 The Department of Health provided more detail about the standards and requirements for suppliers to be approved through the GPSoC process in its 16 July memorandum. See EV 147 (HC 422–III) , section 5.17.

310 See Connecting for Health, *Additional Supply Capability & Capacity Framework Agreement*, 26 March 2007. Clinical systems specified in the tender include hospital and GP administration systems, e-prescribing, integrated care planning, a range of departmental systems and systems for specific patient groups including oncology and renal patients.

311 See Ev 140 (HC 422–III) and Q 470.

312 Q 471

contract.[313] Dr Jon Orrell, a GP, commented that GpSoC had "brought the programme back from the brink of disaster".[314]

Shifting the balance of power: future prospects

203. The programme's leaders clearly acknowledged the need for a balance between central and local input into the development of DCR systems.[315] It is likewise clear that recent initiatives such as NLOP and GPSoC have increased local accountability and introduced choice for some users. Yet many witnesses argued that the balance is still not right, and that more needs to be done to increase local ownership of the programme.[316] This argument seems particularly compelling given that many of the national elements of the programme have been completed, while local deployments are the main challenge for the future.

204. In this context witnesses made several suggestions for further increasing the local ownership of the programme:

a) Frank Burns proposed that **all local organisations should be given a choice of new systems**, rather than having to wait for the delivery of products, such as Lorenzo, which have been badly delayed. Mr Burns argued that as long as interoperability between systems can be assured, it does not matter which specific system is installed in each organisation. However, he acknowledged that existing LSP contracts might make it difficult to increase choice in the short term.[317] Richard Granger did state that if further delays occurred to the delivery of Lorenzo then the Millennium system would be made available to hospitals in the three CSC clusters.[318]

b) Other witnesses suggested that Connecting for Health should set **central standards** for new systems which could then be purchased through a **local procurement** process. Dr Martyn Thomas stated that central standards for interoperability would be crucial to ensuring that records could be shared, but that central accreditation of new systems need not prevent procurement and implementation from taking place locally.[319] Frank Burns recommended developing a national "catalogue" of approved systems for local organisations to choose from, similar to the approach adopted for GPSoC.

c) Frank Burns argued that the NPfIT Local Ownership Programme, which devolves responsibility for delivery to SHAs, did not go far enough. He argued that **accountability should be further devolved to PCTs** if increased local ownership was to be achieved.[320]

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313 Q 99

314 Ev 162

315 Q 583

316 Q 520

317 Q 556

318 Q 576

319 Q 108

320 See Q 520 and Q 527

Security, reliability and consent

205. Although the ultimate goal of implementing shared DCR systems is some way from completion, a number of local component systems have been successfully deployed. As a result, the Committee was able to examine some of the operational challenges raised by DCR systems. In particular, we heard evidence on:

- Plans for safeguarding the **external security** of shared record systems;
- The importance of ensuring that DCR systems and the networks which support them have high levels of **reliability**, especially as dependence on IT systems for clinical purposes increases;
- The challenge of maintaining operational security as the number of people with access to patient records increases. A particular issue was the use of **smartcards** to access DCR systems; and
- The appropriate model for **patient consent** for the creation and sharing of local records.

Technical security

Security targets

206. Questions were raised about the external security of DCR systems, particularly in light of the intention to share detailed and often sensitive health information between organisations. Dr Martyn Thomas was critical of the apparent lack of targets for protecting security, arguing that this would make it difficult to hold suppliers to account:

> ...if you do not know how tolerable it is for a security breach to occur, you do not know how much effort you need to put into building systems that are adequately secure to meet your targets...[321]

207. But suppliers told us that no specific security targets existed simply because no breaches of security were acceptable. Guy Hains of CSC explained that,

> Both parties understand that no system is foolproof, but in terms of any weaknesses that we find in our system, or is found through audit, we are contracted to remedy it quickly. Any issue where we do not remedy will be a failure by us as a contractor...it is a zero tolerance environment.[322]

208. Mr Hains also argued that suppliers have clear general security standards to meet, with regard both to protecting systems from outside attack and to the encryption of data being transferred between DCR systems.[323] He also pointed out that LSPs undertake "ethical hacking" to test their security systems, commenting:

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321 Q 139

322 Q 315

323 Q 280

> We are trying to break our own systems and we use the brightest and best...on a global basis.[324]

System architecture

209. The Committee also heard that technical security will be more difficult to maintain because of the centralised architecture of the data storage and transfer systems designed by LSPs. According to witnesses, regional data storage centres and the use of the national network to share information will make even "local" DCR systems substantial targets for attack.[325] The perceived problem was summarised by the Foundation for Information Policy Research:

> It is a principle of security engineering that we can build system with functionality, scale or security—or indeed with any two of these attributes, but not all three. Secure and highly functional systems have to be local, or compartmented.[326]

210. But officials and suppliers argued that the architecture of DCR systems would indeed be compartmented. Richard Granger commented that the planned architecture for data storage and transfer had been "incorrectly" presented as "monolithic" by commentators. Guy Hains of CSC agreed that building more local or more compartmented systems made maintaining security easier, but argued that this is precisely the aim for LSPs in designing DCR systems:

> ...it is not one large monolithic system...it is absolutely the case that more modular, simpler and smaller systems are more easily protected and upgraded in future. That is exactly the approach we have taken. There is emphasis on keeping tight controls and boundaries and...firm levels of control over message-passing and encryption, making sure that the connectivity that we create is safe. That is the essence of the design.[327]

System reliability

211. Related concerns were raised about maintaining the reliability of DCR systems and preventing systems from crashing or data from being lost. The scale of the potential dangers posed by reliability problems was highlighted by a power failure at a CSC data storage centre in Maidstone in July 2006. 72 PCTs and 8 hospitals lost access to their administrative records systems for several days when back-up systems also failed.[328]

212. Some witnesses argued that failures of this type would be increasingly likely as the complex and interconnected systems which make up the DCR are developed and joined together.[329] Professor Brian Randell told the Committee that:

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324 Ibid

325 Ev 165

326 Ev 65

327 Q 313

328 *North West and West Midlands CSC Maidstone Data Centre Issue*, Connecting for Health Press Release, 31 July 2006

329 Ev 165

> My specialist friend...has done a lot of work on estimating failures. As a guesstimate, not estimate, he said that NPFIT would be likely to fail about once every four days.[330]

213. But the Department of Health strongly defended the likely reliability of DCR systems, arguing that Professor Randell's comment was "not supported by any evidence".[331] Officials also pointed out that the failure at the Maidstone centre had been an isolated incident and that general system reliability was adequate. Richard Granger told us that CSC had been fined £3 million as a result of the Maidstone incident and that the company had since "doubled the amount of resilience" within their data storage system.[332] He described such difficulties as "growing pains" and dismissed predictions of wider reliability problems as "scaremongering".[333] He also praised the reliability of the N3 network and the data transfer system which will support local DCRs:

> BT run both the network and the core national messaging systems and there is a very strong body of evidence from the published service availability data for both those pieces of national infrastructure that not only do they work but they have the level of reliability and dependability which is appropriate to the task.[334]

214. Guy Hains told us that CSC had learnt lessons from the Maidstone incident and had increased the resilience of its systems as a result. He stated that the maximum time limit for resolving system failures had been reduced to 24 hours, with shorter limits for key clinical areas. He also pointed out the importance of developing "contingency and manual procedures" to ensure that clinical services could be maintained in the event of system failure.[335] Finally, Mr Hains stressed that no data had been permanently lost as a result of the Maidstone power failure.[336]

Smartcards

215. Many of the planned operational security measures for DCR systems are the same as those described for the SCR in Chapter 3. Likewise, many of the debates about the likely impact of systems such as role-based access controls described in Chapter 3 apply to the DCR as well as the SCR. Rather than repeat these arguments, we focus in this section on an operational security measure with particular significance for the DCR: smartcard access.

216. The debate about the use of smartcards was ignited when an acute trust in Warwickshire authorised staff in its A&E department to share smartcards when accessing the trust's newly installed PAS application.[337] This was in clear breach of the principle of a unique smartcard for each user. Officials told us that the decision to allow sharing,

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330 Q 325

331 Ev 147 (HC 422–III), Annex 1

332 Q 635

333 See Q 34 and Q 629 respectively

334 Q 629

335 Q 326

336 Q 317

337 See *Progress Report on Solution to Smartcard Sharing*, South Warwickshire General Hospitals Trust Board papers, 4 January 2007. The PAS system installation (of the "transitional" iPM system) was carried out by CSC on 11 December 2006.

authorised by the board of the trust, had now been reversed.[338] Connecting for Health also stated that no breach of confidentiality had occurred as a result of the incident.[339]

217. The Assistant Information Commissioner acknowledged that local security breaches of this type had occurred and stated clearly that the sharing of smartcards represented an unacceptable breach of operational security systems:

> ...there have been some graphic examples where perhaps security precautions have been circumvented by people logging on for a whole shift, using one card rather than their own cards. That must be stamped out; there cannot be any of that.[340]

218. But other witnesses argued that the misuse of smartcards would prove inevitable unless they could provide immediate access to systems. Dr Paul Cundy commented that unless "instantaneous" access to DCR systems could be achieved, smartcards would inevitably be seen as an "obstacle" to clinical processes, particularly in a busy, multidisciplinary environment such as A&E.[341] It is notable that the justification given for sharing smartcards by the acute trust board in Warwickshire was that access to the new PAS application could take between 60 and 90 seconds.[342]

219. CSC, the LSP for the West Midlands area, acknowledged that smartcard sharing had resulted from slow access times. Guy Hains commented:

> The sharing of smart cards was really about the fact that the system did not provide a sufficiently immediate log on for people who wanted to use the system quickly...we recognise the need for a smart card log on procedure of 10 seconds.[343]

220. Richard Granger told us that Connecting for Health had considered using "slicker" systems than smartcards for accessing DCR systems. He explained that facial pattern recognition, retinal recognition or fingerprint recognition systems had all been examined. However, Mr Granger concluded that facial pattern and retinal recognition had been rejected because the underpinning technology remained "immature", while fingerprint recognition was impractical in a clinical environment where many staff wear gloves.[344]

Consent systems

221. The majority of the evidence we received on patient consent related to the SCR rather than the DCR and we discuss this in Chapter 3. Witnesses argued that the prospect of a nationally available SCR tended to raise more concerns about privacy than that of locally shared DCRs. Frank Burns commented:

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338 Q 28

339 See *Response to media reports about the use of smartcards*, Connecting for Health Press Release, 1 February 2007

340 Q 224

341 Q 141

342 See *Progress Report on Solution to Smartcard Sharing*, South Warwickshire General Hospitals Trust Board papers, 4 January 2007. In its 16 July memorandum, the Department pointed out that access times for the PAS application in questions have been "significantly reduced" in the past year—see EV 147 (HC 422-III) , section 6.28.

343 Q 280

344 Q 28

> I think that the only reason you have been having the [consent] debate is because they have gone for a national model with the summary care record. If they pursue a local approach to development of a detailed care record...you would be able to explain to people why their own GP needs to share information with a specialist at the hospital...and in that context I think the public would be much less concerned.[345]

Shared records

222. In spite of this, a number of witnesses did highlight the need for robust local consent procedures, particularly for the sharing of information between the separate systems which make up the DCR. The Royal College of GPs argued for "organisational boundaries around information" so that data could not be shared between organisations without the patient's explicit consent.[346] This suggestion, similar to the 'amber' consent position for the SCR, was also put forward by that BMA and the British Computer Society.[347]

223. The Department stated that patients would be able to limit access to their detailed records in this way:

> ...people can choose to have their information held electronically but not accessible to anyone outside the organisation that created it—thereby recreating an electronic version of the status quo.[348]

Local records

224. This would mean that patients could in effect opt out of having a shared DCR. However, the Department pointed out that as the local systems which make up the DCR are introduced, an increasing amount of information, particularly from hospitals, will be stored electronically on LSP servers.[349] Thus it will often not be possible to prevent patient-identifiable information from being placed on LSP records systems. The Department stated that:

> Individuals may ask those who are providing care for them whether or not it is possible to withhold information from the new IT systems but in many cases this will be impracticable. Some forms of care, X-rays, laboratory tests etc will generate records within the new systems automatically and the only way to prevent this is to choose not to have that particular care or treatment.[350]

225. Richard Granger highlighted the problems that would be caused by allowing patients to opt out of any form of electronic record storage:

> If an individual is so distressed that they do not want an x-ray to be conducted electronically, I think ministers would need to decide whether it was indeed in the

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345 Q 527

346 Ev 93

347 See Ev 43 and Ev 38 respectively

348 Ev 6

349 We were told that both images and laboratory test results may be stored on remote LSP servers.

350 Ibid

public interest to maintain wet film processing, a 19th century technology, for these distressed individuals.[351]

Sealed envelopes

226. The Department also commented that local "sealed envelopes" will be available to safeguard particularly sensitive information held in DCR systems.[352] But Guy Hains of CSC stated that exact specifications for DCR "sealed envelopes" had not yet been given to LSPs by Connecting for Health and that the technology was unlikely to be available before 2009.[353]

Conclusions and recommendations

Vision and potential

227. Patient record systems which record detailed clinical information that can be shared or joined electronically within and between a range of local organisations are the "holy grail" for NPfIT. Such Detailed Care Record (DCR) systems can bring dramatic improvements to the safety, quality and efficiency of NHS care, not only through faster access to and sharing of patient information, but also by supporting key clinical processes such as imaging and prescribing. More sophisticated clinical systems can further improve care, for example by supporting clinical decision-making and providing automatic messages and alerts to challenge unsafe practices.

228. Achieving the widespread uptake of DCR systems is therefore the single most important advance that the NHS can make towards the provision of faster, better integrated and more patient-centred care. The potential benefits from detailed systems are wider than those offered by the national SCR system. Moreover, the goal of providing DCR systems to all NHS providers in England was clearly set out in the specification document on which NPfIT was based and tendered. It is thus on NPfIT's success in implementing DCR systems that the programme's effectiveness should ultimately be judged.

229. Yet there is a perplexing lack of clarity about exactly what NPfIT will now deliver. It is not clear what information will be recorded and shared on DCR systems, nor the range of organisations that will be able to share information. Suppliers told us there will be significant variation between the size of different areas. The Department stated that DCR systems may be confined to areas as small as a single hospital or as large as an entire SHA. While local control over the new systems is a desirable goal, it is surprising that the architects of the DCR were not able to provide a clearer vision of what is planned. There is an explanatory vacuum surrounding DCR systems and this must be addressed if duplication of effort at a local level is to be avoided. We recommend that Connecting for Health:

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351 Q 639

352 Ev 7

353 See Qq 302–306

- Publish clear information about its plans for DCR systems, stating in particular what area will be covered by shared records and what degree of information sharing will be possible; these plans should make reference to the original specifications for the Integrated Care Records Service, making clear how the scope of the project has changed since 2003; and

- Set out clear milestones for achieving the increasing levels of interoperability and automation offered by DCR systems.

Progress and implementation

230. Progress on delivering the various elements of shared DCR systems has varied considerably. Projects such as the N3 network and the deployment of Picture Archiving and Communication Systems are on the way to successful completion: Connecting for Health deserves some credit for these successes. However, the continuing delays to delivering new Patient Administration Systems (PAS) and functions such as electronic prescribing in hospitals are a major concern. As a result of such delays, the shared DCR remains a distant prospect. Only BT provided an estimate, 2010, of when shared records will be available. This timetable only applies to the London area, however, and the level of information sharing which will be possible by this date was unclear.

231. There have been many causes of the delays in delivering new systems. One of these has been the expansion to the scope of the programme since 2002. Changes were perhaps inevitable given the scale of NPfIT, but it is disappointing that essentially administrative applications such as Choose and Book were given priority ahead of clinically useful DCR systems. It is also apparent that the original timescales for deploying DCR systems were over-ambitious and did not take sufficient account of the complexity of replacing existing systems. The failure to give hospitals responsibility for implementing their own systems, and the lack of focus on changing local working practices to accommodate newly deployed systems, have also caused delays.

232. The lack of progress on implementing new hospital PAS software, which has in turn prevented suppliers from deploying more sophisticated clinical systems, remains the biggest obstacle to delivering shared local records. The implementation of new hospital systems is more than two years behind schedule. In London and the South, where Cerner's Millennium system is to be deployed, there is some evidence of progress, as well as a timetable for completing implementation in London. Yet in the remaining three clusters, which are awaiting iSoft's Lorenzo product, delays drag on. Such delays have left many hospitals relying on increasingly outdated systems for their day-to-day administration. Most worryingly, the failure to deliver systems on time has reduced the confidence of local clinicians and managers in the programme, something which has itself contributed to delays.

233. We recommend that Connecting for Health:

- Ensure that all LSPs publish detailed timetables for delivering new PAS applications, electronic prescribing systems and shared local record systems, indicating what level of information sharing will be possible when DCRs are first implemented; and

- Set a deadline for the successful deployment of the Lorenzo system in an NHS hospital, making clear that if the deadline is not achieved then other systems with similar capability will be offered to local hospitals.

The way forward

234. In light of a range of concerns, including the delays to elements of the DCR programme, a number of witnesses called for an independent review of the whole of NPfIT. Whilst we understand the reasons for this, we do not agree that a comprehensive review is the best way forward. First, many of the questions raised by the supporters of a review would be addressed if Connecting for Health provided the additional information and independent evaluation which we recommend in this report. Secondly, the programme has already been scrutinised by the National Audit Office, the Public Accounts Committee and ourselves. We therefore recommend that:

- The implementation of DCR systems be addressed in the short term by increasing both the local ownership and the professional leadership of the programme; and

- The ongoing review by Lord Darzi on the future of the NHS include in its remit the long-term prospects for using electronic systems to improve the quality of care, particularly for the growing number of patients with long-term conditions.

235. The Committee recognises the need to maintain a balance between central and local input into the development of DCR systems. We acknowledge the success of NPfIT's national leadership in ensuring economies of scale and effective contract management. However, we disagree that this highly centralised approach is necessary to ensure consistent development of new systems across the NHS, provided that sufficient attention is given to nationally agreed technical and clinical standards. It is also clear that centrally driven implementation of local systems has stifled local activity and caused frustration and resentment at trust level. The successful delivery of DCR systems depends upon the ability of Connecting for Health to harness the benefits from local as well as national input, something which it has not achieved so far.

236. There are already signs of a change of approach to increase local ownership of system implementation. Accountability is being devolved through the NPfIT Local Ownership Programme and control for some users is being increased through GP Systems of Choice. These measures are welcome but overdue. There is a need to go further and faster with reforms of this type. We recommend that:

- Connecting for Health devolve responsibility for performance managing implementation of all NPfIT systems to Strategic Health Authorities (SHAs);

- SHAs devolve responsibility for operational deployment by giving individual hospital trusts control over implementing their own new systems. SHAs should also devolve responsibility for implementing shared record systems across local health communities to their constituent Primary Care Trusts (PCTs);

- **SHAs, PCTs and hospital trusts be given the authority to negotiate directly with LSPs and to hold suppliers to account, so that local organisations are not given responsibility without power; and**

- **Connecting for Health offer all local organisations a choice of systems from a catalogue of accredited suppliers, as far as this approach is possible within the limitations of existing contracts.**

237. **Connecting for Health's own role should switch as soon as possible to focus on setting and ensuring compliance with technical and clinical standards for NHS IT systems, rather than presiding over local implementation. Clear standards would allow systems to be accredited nationally but would also ensure that local trusts have a choice of system and control over implementation.**

238. **Technical standards should cover system security and reliability but should focus in particular on ensuring full interoperability between accredited systems. Comprehensive interoperability standards should guarantee that data can be seamlessly exchanged between systems whilst ensuring that users are not committed to a single supplier. In order to develop transparent technical standards, we recommend that Connecting for Health:**

- **Establish an independent technical standards body responsible for setting the interoperability requirements for data exchange for all systems deployed in the NHS. These standards should be published and subjected to full external scrutiny;**

- **Require all system suppliers to the NHS to meet and demonstrate conformity with these standards. Systems should be "kite marked" or classified to give details of their compatibility; and**

- **Work with industry and academia to establish an independent technical standards testing service to evaluate and accredit systems for use in the NHS.**

239. **Safe and effective data sharing, the fundamental aim of DCR systems, also requires a more standardised approach to the recording of clinical information. Such an approach is at the heart of ensuring real interoperability between systems and is vital if data from DCR systems is to be used as a basis either for the SCR or for research. The NHS Data Dictionary and the SNOMED CT coding system are important to achieving more consistent recording of patient information. We recommend that Connecting for Health publish a timetable for introducing SNOMED CT across the NHS.**

240. **But Connecting for Health must do much more to ensure that the recording of detailed clinical data is standardised. Professionally developed datasets and agreed approaches to the structure and content of detailed records are urgently needed for each of the main clinical specialties and for use in a range of different care settings. Developing such standards will require close collaboration with Royal Colleges and other professional bodies. We recommend that Connecting for Health work with professional groups to:**

- Identify the information standards which will be required within their specialty area; and
- Develop and implement consensus-based clinical information standards.

241. Separate clinical records on an individual patient can only be combined safely if each person can be accurately identified. The introduction of the new NHS number as the unique patient identifier and its allocation at birth through NHS Numbers for Babies is therefore a significant achievement. Yet the value of this work and the future integrity of clinical information will be undermined if organisations are unable to retrieve an individual's NHS number when they need to use it or to allocate temporary NHS numbers for use in emergencies. We recommend that:

- The Department of Health set a timetable for mandating the use of the correct NHS number on all clinical communications, and make this a performance measure for all NHS organisations;
- Processes are introduced to allow temporary NHS numbers to be allocated which can subsequently be reconciled with the patient's permanent NHS number through the Personal Demographic Service; and
- Systems are maintained to treat patients under a separate, pseudonymous NHS number where this is necessary.

Security, reliability and consent

242. The resilience of new systems will be enhanced by distributing data across a range of hosting centres. Suppliers assured us that systems will be distributed in this way but the impact of the power failure at the Maidstone data centre, which affected 80 trusts, suggests otherwise. We recognise that lessons have been learned from the Maidstone incident. Nonetheless, we recommend that Connecting for Health instruct suppliers to publish details of all significant reliability problems along with a full incident log.

243. The sharing of unique smartcards between users is unacceptable and undermines the operational security of DCR systems. However, we sympathise with the A&E staff who shared smartcards when faced with waits of a minute or more to access their new PAS software. Unless unacceptably lengthy log-on times are addressed, security breaches are inevitable. We recommend that Connecting for Health:

- Ensure that suppliers have clear plans for achieving access times compatible with realistic clinical requirements for all of their systems; and
- Continue to monitor the potential for introducing more sophisticated access systems, such as facial pattern recognition, in busy areas such as A&E.

244. The Department has indicated that explicit consent will be required before DCR information can be shared between separate organisations. The Committee supports this approach and recommends that the consent model for the shared DCR be communicated to patients as clearly and as early as possible.

245. **However, if sensitive information is to be stored and shared on DCR systems, it is important that local "sealed envelope" systems are developed and tested as soon as possible. We were concerned to hear that suppliers have not yet received specifications for local "sealed envelopes". We recommend that Connecting for Health provide such specifications as a matter of urgency and set a clear timetable for the introduction of this technology at a local level.**

5 The Secondary Uses Service

246. Storing and managing health information electronically can bring a range of additional benefits alongside improvements to direct patient care. The management and commissioning of health services, as well as clinical audit and research, known collectively as "secondary uses", can all be enhanced by quicker and easier access to health information. These secondary uses are profoundly important to improving care: as one witness put it, "there is no distinction to be made between health services and research for effective health services".[354]

247. In order to regulate access to electronic health databases for such "secondary uses", the NCRS will include a national application known as the Secondary Uses Service (SUS). In this chapter we examine the SUS, focussing particularly on its potential impact on clinical research. We look at:

- **Descriptions** of the SUS, including both its current and intended future form, and a discussion of the **potential** offered by the SUS; and
- The existing **governance and consent** arrangements which regulate access to data for "secondary" uses, and how these could be improved.

Description and potential

248. In this section we examine:

- How the SUS works at present;
- Plans for the development of the SUS, particularly by giving access to data from the SCR and DCR systems for secondary purposes; and
- The impact of access to NCRS data on the SUS.

How the Secondary Uses Service currently works

249. In its current form, the SUS has taken over many of the functions previously provided by the NHS-Wide Clearing Service (NWCS), which was decommissioned in December 2006.[355] Like the NWCS, the SUS mainly uses data provided by Hospital Episode Statistics (HES), which are derived from existing PAS applications and paper records. HES data includes administrative information and some clinical information, for example about diagnoses and procedures, presented in a coded form. The existing SUS also accesses aggregated administrative data from outpatient clinics.

250. The data currently provided by the SUS are used for a range of management purposes. In particular, SUS datasets are used to support Payment by Results by exchanging activity and price information between commissioners and providers.[356] SUS data can also be used

354 Q 334

355 *SUS replaces decommissioned NWCS ClearNET Service*, See Connecting for Health press release, 19 January 2007

356 See www.connectingforhealth.nhs.uk/systemsandservices/sus/

for a range of other purposes including clinical audit and research. However, existing data sources such as HES do not provide detailed clinical information, and their value for research is therefore limited. The current functions of the SUS are much the same as those previously offered by the NWCS.

Plans for the development of the Secondary Uses Service

251. In future, it is intended that information from both SCR and DCR systems will be made available through the SUS. Thus the SUS will be a key element of the wider NCRS. BT described the SUS as a system for providing "anonymous patient data for research and planning purposes".[357] The Department of Health described the goal of the SUS as "to rationalise data abstraction, data flows, data management, analysis and reporting". According to the Department, SUS data will support "healthcare planning, commissioning, public health, clinical audit, benchmarking, performance improvement, research and clinical governance".[358]

252. In order to achieve this, the SUS will access data from a widening range of sources, both national and local, including clinical data from the SCR and DCR. Data extracted from these rich sources will be collated by the SUS, pseudonymised so that identifying data is removed, and then presented to users in a searchable format. Users will be able to access the SUS online and make specific data requests. As with the SCR and DCR systems, users will require a smartcard to access the SUS and role-based access controls will regulate the level of access for each user.[359]

The impact of NHS Care Records Service data on the Secondary Uses Service

253. The expected growth in the amount of clinical information available electronically, through the introduction of SCR and then of DCR systems, will dramatically increase the usefulness of the SUS. At present, SUS data is coded manually and contains very little clinical detail, while information from different care settings cannot be integrated. The SCR and DCR, by contrast, have the potential to provide detailed, integrated clinical data, made available to the SUS promptly and without the need for laborious manual coding procedures. Such data would be significantly more detailed and of a profoundly higher quality than that which the SUS currently offers. For this reason, the Department of Health said that the introduction of SCR and DCR systems "represents a major opportunity" for expanding the scope and usefulness of the SUS.[360]

The threat to privacy

254. As with other EPR systems, however, the increasing availability of health information through the SUS will bring new risks as well as new opportunities. Witnesses expressed particular concerns about the possible effects of increasing the breadth and depth of data

357 Ev 128 (HC 422–III)

358 Ev 8

359 Ibid. We discuss the psedonymisation process, which has attracted considerable debate, in more detail below.

360 Ev 8

held electronically while simultaneously widening access to this data. Dr Martyn Thomas argued that easier access to data could make breaches of privacy more frequent and more serious. He pointed out that:

> ...a lot of patients whose privacy was never really under threat with paper records, because it would simply have been too hard to go and trawl through large numbers of those records, are now potentially at risk...[361]

255. Professor Douwe Korff warned that the increasing availability of health information would lead to a corresponding increase in the range of organisations seeking access. He argued that:

> Once the data exist in this kind of accessible form there will be pressure...to identify illegal immigrants in this way; and there will be pressure from the police and certainly the anti-terrorist authorities...It is a recipe for disaster.[362]

The research opportunity

256. Other witnesses were much more positive, pointing out the many opportunities offered by access to detailed health information via the SUS. In particular, the benefits for health research were underlined. Research organisations consistently argued that the depth and breadth of data accessible via the SUS could act as a "unique selling point" for UK research.[363] The Academy of Medical Sciences observed:

> The development of NPfIT and EPR offer unparalleled opportunities for research that could have a real and significant impact on future health in the UK.[364]

257. The Department of Health also acknowledged the great potential of the SUS to improve health research in its January 2006 publication, *Best Research for Best Health*. The paper envisaged that the UK could offer "unique benefits" as a site for clinical research, because of its plans for detailed electronic records systems, and due to the fact that the NHS provides care for the vast majority of citizens. *Best Research for Best Health* concluded:

> The new national IT system for the NHS in England offers a unique and unrivalled opportunity for research into health that the Department of Health is determined to realise.[365]

258. A UK Clinical Research Collaboration R&D Advisory Group to Connecting for Health has also been established to helped ensure that the research opportunities offered by SUS are maximised.[366] As part of this work, Connecting for Health commissioned a series of research simulations to assess the impact of expanding SUS data on different types of

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361 Q 113

362 Q 230

363 See Ev 17, Ev 121 and Ev 126

364 Ev 12

365 Department of Health, *Best Research for Best Health: A new national health research strategy*, 25 January 2006, p.28

366 See www.ukcrc.org/activities/infrastructureinthenhs/nhsitprogrammes/advisorygroup.aspx for more details

research. The simulation outcomes were published by the UK Clinical Research Collaboration's in June 2007.[367]

259. Witnesses from research organisations described a range of specific types of research which would benefit from improved access to electronic health data, including:

- Research into **public health**, including both risk factors and interventions;[368]
- Studies looking at the **side effects** of particular drug treatments. Researchers argued that the association between non-steroidal anti-inflammatory drugs and cardiovascular disease could have been discovered more quickly using electronic data;[369]
- **Genetic** research. Researchers argued that the UK is "uniquely positioned" to conduct genetic studies;[370] and
- Research linking maternal health with children's incidence of disease in later life, for example the effects of complications during pregnancy on the incidence of schizophrenia.[371]

Maximising research benefits

260. While the potential is huge, research organisations also warned that the opportunities to improve research would be lost if excessive constraints were placed on access to data or if capacity for linking data from diverse sources was limited. The Academy of Medical Sciences (AMS) commented:

> ...disproportionate constraints on the use of health information can compromise the quality and validity of research results, leading to potentially misleading claims, or even costing lives.[372]

261. Researchers therefore made a range of suggestions for ensuring that the opportunities offered by the SUS are maximised. These included:

a) Establishing a single **unique patient identifier** for each NHS patient and mandating its use whenever a patient comes into contact with the health service. Professor Carol Dezateux described this as the "most critical factor" in improving research through the SUS as it would allow previously separate parts of the patient record to be integrated.[373]

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367 UK Clinical Research Collaboration, *The potential of electronic patient records: research for patient benefit*, 7 June 2007

368 See Q 335: Dr Mark Walport of the Wellcome Trust commented that "The greatest advances in health have come from public health measures...The opportunity in England to have potentially 50 million health records with good record linkage offers enormously important opportunities for improving patient health."

369 Q 335

370 Ibid

371 Ibid. Professor Simon Wessely pointed out that research of this type often has to be carried out in Scandinavia because of the lack of linked electronic databases in the UK.

372 Ev 12

373 See Q 337. Dr Gill Markham of the Royal College of Radiologists also pointed out (Q 522) that there are benefits to direct patient care of consistently using a single unique identifier.

Lord Hunt expressed confidence that this could be achieved through wider use of the NHS number, describing this as an "unseen but huge advance".[374] The NHS number is discussed in more detail in Chapter 4, above.

b) Achieving **better linkage of databases**, particularly in order to answer complex or unexpected public health questions. Professor Dezateux commented that: "We should not have data sets that are not patient-level and that are not linkable, because we cannot answer the important questions that society wants us to address".[375] Witnesses gave the examples of Denmark and Finland as countries with good database linkage.[376] The Health Protection Agency also argued that better database linkage would help them to monitor public health risks, such as potential infectious disease outbreaks, by accessing relevant clinical data in real time.[377]

c) Improving **public communication** about the research opportunities offered by the SUS and the potential benefits from strengthening the infrastructure which supports research using electronic health data.[378]

d) Updating and strengthening the **governance framework** which regulates access to data for research and other purposes. Witnesses argued for more transparent governance and consent systems which would maximise privacy without constraining research.[379] We discuss these issues in more detail below.

Governance and consent

262. Exploiting the opportunities offered by the SUS will require a careful and balanced approach to governance arrangements for regulating availability of and access to SUS data. Witnesses put forward a range of arguments and suggestions regarding patient consent, pseudonymisation, and other aspects of governance. In this section we look at:

- **Existing measures** for regulating access to SUS data;
- **Doubts and debates** regarding the governance framework, including arguments about the appropriate model for patient consent and the effectiveness of the pseudonymisation of data; and
- **Suggestions for changes** to the governance framework in light of current problems and the expected growth in demand for access to health information.

374 Q 618

375 Q 337

376 See Q 335 and Q 337

377 See Ev 69. The HPA concluded that "The benefits that Connecting for Health could realise for organisations such as the HPA cannot be overstated."

378 Q 337

379 See, for example, Q 342

Existing measures

263. The current framework for regulating access to information through the SUS was set out by officials on 26 April 2007. They commented that the legal framework for the use of data for health research currently permits access through three different routes:

- Information can be made available with **explicit consent** from the patient.
- Access is permitted if information has been **pseudonymised** i.e. if data which could allow an individual patient to be identified have been removed. This is intended to be the usual basis for access to data through the SUS. In the US, a legal distinction has been drawn between fully and partially pseudonymised data. Fully pseudonymised data, from which 18 specific identifiers have been removed and from which the risk of re-identification is extremely limited, is known as "de-identified" information. However, as we discuss below, such data are often inadequate for research purposes. As a result, partly pseudonymised "limited data sets" are also recognised. "Limited data sets" may contain some identifying information but are made available to users subject to contractual and technical limitations, and with the agreement that no attempt will be made to identify individuals.[380] Although this contrast has not been formally recognised in England, the distinction between fully and partially pseudonymised data is used to clarify the discussion below.
- Identifiable or potentially identifiable information can be accessed with specific permission from the **Patient Information Advisory Group**, a body established by the 2001 Health and Social Care Act.[381]

264. Witnesses also pointed out that access to data for research purposes is subject to local controls and ethical approval. Professor Simon Wessely explained:

> ...there is this very complicated system of checks and balances by which we have to be governed...I cannot simply say, "Give me the data" on this that or the other, I have to apply to an ethics committee, a Caldicott committee, an R&D committee and so on.[382]

Doubts and debates

265. Questions and criticisms were raised by a variety of witnesses about the suitability and effectiveness of current access and governance measures. On the one hand, some witnesses argued that current measures do too little to protect patient privacy. The Foundation for Information Policy Research (FIPR), for example, argued that:

380 See http://privacyruleandresearch.nih.gov/ for more details

381 Q 63

382 Q 346

> The UK has so far failed to develop a robust political and legal mechanism for balancing patients' privacy interests with the many requests by others for access to their data.[383]

266. On the other hand, research organisations often argued that regulations are currently too strict and therefore inhibit research. The AMS stated:

> ...confusing legislation and professional guidance, bureaucracy of process and an undue emphasis of privacy and autonomy, are having a detrimental effect on UK research activity...[384]

267. Both sides agreed that patients and the public would benefit from a fuller understanding of the current and potential future use of data for research and other secondary purposes. FIPR commented that:

> ...a gap has opened up between actual practice on the one hand, and the expectations and views of patients on the other... Many more people have access to medical records than most patients realise...Legal challenges are likely as more people become aware of what is happening.[385]

268. The AMS also argued for improving public understanding of how electronic data can be used for research, but contended that this would lead to increased support for relaxing access controls:

> Urgent work is needed to increase public engagement about the value of research using healthcare records...in our discussions with patient representatives there was strong support for research using health data. There was great concern that a vocal minority, loudly proclaiming the right of privacy, might override the unexpressed desire of many people to contribute to the public good.[386]

Consent systems

269. Some witnesses argued that, unless data could be fully pseudonymised, patient consent should be required for data to be used for research purposes. Support for explicit patient consent in such cases was expressed by organisations including the Royal College of Psychiatrists and the Royal College of Surgeons.[387] Professor Douwe Korff went further, arguing that current UK consent procedures may not be strict enough to comply with European law.[388] Helen Wilkinson, founder of the Big Opt Out Campaign, argued that patients should have the right to prevent their data being used by the SUS, even in pseudonymised form. She warned that:

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383 Ev 64

384 Ev 12

385 Ev 63

386 Ev 15

387 See Ev 105 and Ev 109 respectively

388 Q 175

> ...patients tell me that they are prepared to lie about their symptoms, medication...and medical history as they cannot opt out of the DCR or prevent their records being used by the SUS.[389]

270. But other witnesses said that the reliance on specific patient consent should be limited and argued that maintaining or tightening consent requirements could have a negative impact on future research. Obtaining explicit consent, particularly for large studies, can in practice prove impossible.[390] Professor Carol Dezateux commented that consent is often more difficult to obtain from socially disadvantaged or ethnic minority groups, something which can inhibit research, particularly into health inequalities, or even bias research findings.[391] The AMS argued that the rights of individuals to restrict access to their data should not necessarily be seen to outweigh the public benefits of health research:

> It could be maintained that a patient has the right to say 'use my data to treat me, but not to improve care for others'. Or more starkly, 'use evidence from other people's data to treat me, but don't use my data to help them.[392]

Pseudonymisation

271. Questions were also raised about the intention to pseudonymise data made available through the SUS. "Pseudonymisation" is achieved by removing identifying information such as the patient's name, address and contact details. However, as mentioned above, there is a distinction between fully and partially pseudonymised data. Witnesses stated that partial pseudonymisation will often not prevent patients from being re-identified, particularly if information such as the postcode and date of birth are retained.[393] Professor Douwe Korff added that, if full pseudonymisation did not take place, patients' consent should be sought before data were made available:

> The issue hinges on identifiability...When the data used in research...are so flimsily anonymised that it is very easy to re-identify people, in my view they remain personal data and therefore cannot be used without the express, valid and free consent of the data subject.[394]

272. Doubts about pseudonymisation were also expressed by the Assistant Information Commissioner. He admitted that the Information Commissioner's Office had not examined the pseudonymisation techniques which will be used to encrypt SUS data but acknowledged that "we will be asking a few questions" in light of the concerns presented to the Committee.[395] Mr Bamford agreed that if the effectiveness of pseudonymisation could

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389 Ev 192

390 See Ev 13: The AMS gave the example of Professor D Barker's research into the links between conditions during pregnancy and cardiovascular disease. Because of the large sample size and the long period covered by the study, obtaining consent was not always possible. The study demonstrated a link between low birth weight and the risk of type II diabetes.

391 Q 352

392 Ev 13

393 Q 228

394 Q 230

395 Q 238

not be assured then the case for making data available through the SUS would be weakened:

> If it is truly pseudonymised and it is not that easy to look back at the records or bring them together...I do not think it would be open to very much challenge. If the pseudonymisation is not effective then that is a much more open question.[396]

273. Researchers argued that the degree of protection offered by pseudonymisation depended on the type of research being conducted. Dr Mark Walport maintained that full pseudonymisation could completely protect a patient's identity,[397] but he also pointed out that many studies rely for their effectiveness on information, such as the patient's postcode, which might make re-identification possible.[398] It is in this context that partially pseudonymised information, known in the US as a "limited data set", is required. The AMS also pointed out a range of other important uses of identifiable information, including:

- Avoiding double counting of patients;
- Performing longitudinal studies which link risk factors, such as smoking, to health later in life; and
- Validating the quality of data and so the outcomes of research.[399]

274. Researchers therefore stated that the degree to which data is pseudonymised should be maximised but should vary depending on the specific requirements of different research projects.[400] BT, the company responsible for pseudonymisation, confirmed that the amount of data removed could be varied in practice.[401]

275. Professor Carol Dezateux argued that access to partly pseudonymised "limited data sets" for researchers could be balanced by more sophisticated audit of the way in which data is accessed and used, along with clear sanctions for the misuse of data. She pointed out that this will be made easier by the increasing use of electronic databases:

> I can have an audit trail which shows what I, as a researcher, have done with that and which holds me accountable. I would lose my job if I did something wrong. I think you have to have those sanctions.[402]

276. So witnesses were in broad agreement that fully pseudonymised "de-identified" data would not be adequate for many research purposes. Thus the SUS will also need to provide researchers with partially pseudonymised "limited data sets" from which patients could in theory be re-identified. As witnesses pointed out, this increases the need for complementary governance systems to protect potentially identifiable information from abuse, which we discuss below.

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396 Q 236

397 Q 350

398 Q 355

399 See Ev 13–14

400 Q 355

401 Q 496

402 Q 343

The Patient Information Advisory Group

277. Finally, witnesses expressed concerns about the Patient Information Advisory Group (PIAG), the body which considers requests for access to health information in cases where researchers require identifiable data and consent cannot be gained. Professor Douwe Korff described PIAG as "quite easy about giving access" to identifiable information and argued that the group should do more to protect patient privacy.[403] But Professor Simon Wessely expressed the opposite view, arguing that PIAG was sometimes too protective of patients' privacy rights.[404] A recent report by the AMS, *Personal data for public good*, put this point more explicitly:

> ...PIAG currently stresses its role on protecting privacy and confidentiality, without equal emphasis on the public benefits derived from well-conducted research. The Academy considers that PIAG should more actively promote its role as a facilitator of research.[405]

278. Professor Wessely also described PIAG as an "emergency measure", established at short notice in light of changes to General Medical Council guidance on the use of data in research.[406] In addition, Dr Mark Walport argued that PIAG was initially seen as a temporary organisation, a view which has now changed:

> ...when PIAG was set up it was the philosophy that somehow PIAG might only be needed for a short time because we were moving to a world where consent would be possible for everything. I think it has been recognised that that really is not the case, that there are always going to be unforeseen questions.[407]

Suggestions for change

279. In light of these and other concerns, a number of witnesses suggested changes to the regulatory and governance arrangements for access to SUS data. Importantly, the case for reform was put forward both by exponents of greater protection for patient privacy, such as FIPR, and by research organisations seeking to improve access to information.[408] The following were amongst the suggestions for reforming governance systems:

- Introducing a system of **class approval** so that organisations such as PIAG could make judgements about granting access to identifiable data which would apply to whole categories of research, rather than considering each individual project in isolation. This was also referred to as a **community assent** model;[409]

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403 Q 240 [Professor Douwe Korff]

404 Q 363. PIAG told us that of the 250 applications which it has received to date, 70% have been approved.

405 Academy of Medical Sciences, *Personal data for public good: using health information in medical research*, January 2006, pp.4–5

406 Q 364

407 Q 365

408 See Ev 64 and Q 365 respectively

409 See Qq 364–365

- Introducing a national **Information Governance Board** to oversee the arrangements for regulating access to health data. It was suggested that PIAG, or a successor organisation, could be reconstituted as a permanent subcommittee of the national Board. [410] In a late submission, PIAG stated that "the creation of a new national advisory body, which will absorb PIAG and other similar groups" is likely to take place in future. The Department of Health, however, did not mention this;[411]

- Extending the use of **third party brokerage** as a system for protecting the privacy of health information. This approach was supported both by researchers and by the Assistant Information Commissioner;[412]

- Providing **full pseudonymisation** of data, for example so that only the patient's year of birth and home area are retained;[413] and

- A **full review of governance systems**, examining the role of local ethics committees, Caldicott Guardians, PIAG and the relationships between them. Witnesses suggested that this would help to bring "greater coherence" to a system which has developed in an "ad hoc" fashion.[414]

Conclusions and recommendations

280. **The Secondary Uses Service (SUS), which succeeded the NHS-Wide Clearing Service, has for some years helped to improve the health service by providing access to and analysis of data for commissioning, management and audit purposes. However, the development of the SCR and DCR will allow access to clinical data which are timelier, better integrated and of a profoundly higher quality than those currently available. This will transform the SUS and offers significant benefits, most notably for health research. In particular, if the highly detailed data captured by DCR systems can be made available through the SUS then the possibilities for new and improved research are outstanding.**

281. **The Department has acknowledged the need to take advantage of the research opportunities offered by the SUS and has established a partnership with the UK Clinical Research Collaboration to achieve this. We welcome this, but researchers nevertheless told us that much more could be done to maximise these opportunities. We recommend that Connecting for Health:**

- **Mandate the use of the unique patient identifier, the NHS number, in all health service interactions in England;**

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410 Q 365

411 EPR 81, unpublished.

412 See Q 343 and Qq 242–3 respectively. Professor Carol Dezateux described (Q 343) the use of a third-party broker in new-born HIV testing: "The laboratory in my hospital sends information to the Office of National Statistics, they link the data, they remove the identifiers, and only then can the laboratory test the samples, when all this has been removed, so that it is very secure."

413 Q 229

414 Q 365

- **Develop appropriate linkage between databases within and beyond the SUS. This would also have benefits for non-research activities such as health protection;**

- **Ensure that the development of clinical information standards, which we recommended in Chapter 4, takes account of the needs of research; and**

- **Initiate a campaign of public engagement so that both the opportunities and risks from using health data for research purposes are better understood.**

282. **Increasing access to health data brings new challenges for safeguarding patient privacy. It is therefore vital that the systems which regulate availability of, and access to, data through the SUS are safe and effective. Governance systems must strike a difficult balance between the need to protect patient privacy and the need to take advantage of the increasing availability of data, between safeguarding individual rights and promoting the public good. Unless such a balance can be struck, there is a risk either that the potential of the SUS will not be realised, or that public confidence will be damaged.**

283. **There are a number of weaknesses within current access and governance systems. While explicit patient consent is the ideal means of allowing access to data, it is often impossible to ask for consent in practice, particularly for studies using historical data. Pseudonymisation is a good idea in principle, but full pseudonymisation is only possible in some situations because potentially identifying data are often needed for effective research. It follows that some research will continue to require access to partially pseudonymised data in situations where obtaining explicit consent is impossible. However, the Patient Information Advisory Group (PIAG), which considers such requests, remains a temporary body. PIAG has attracted criticism both for its processes and for its decisions.**

284. **There is an urgent need to address these problems, especially as the amount and type of data potentially available through the SUS will proliferate rapidly in future. We recommend that the Department of Health conduct a review of both national and local procedures for controlling access to electronic health data for "secondary" uses. In particular, the review should examine:**

- **How best to balance the opportunity to improve access to data for research purposes with the ongoing need to safeguard patient privacy;**

- **Whether to establish a national Information Governance Board to oversee the arrangements for access to data for secondary uses;**

- **The case for establishing a permanent body to succeed the Patient Information Advisory Group and whether this should be a subcommittee of the national Board;**

- **The effectiveness of the pseudonymisation process proposed by Connecting for Health and its suppliers, which should be subject to independent public evaluation;**

- **What compensating controls, such as third party brokerage, should be used to protect patient privacy in situations where research must be conducted with partially rather than fully pseudonymised information; and**
- **How governance arrangements for access to data for research purposes should differ from those which apply to other "secondary" purposes, such as immigration and counter-terrorism.**

Conclusions and recommendations

Electronic Patient Record systems

1. The National Programme for IT (NPfIT) is a complex and ambitious set of projects intended to transform the use of information technology in the NHS. At the heart of the programme is the NHS Care Records Service (NCRS), which aims to introduce a range of electronic patient record (EPR) systems. EPR systems offer significant potential improvements to the safety, quality and efficiency of care and are being implemented in most health systems in the developed world. (Paragraph 40)

2. NPfIT is characterised by a centralised management structure and large-scale procurement from private suppliers. This approach aims to offer improved value for money and to address the previously patchy adoption of IT systems across the health service. The Department defended the progress made by NPfIT to date, arguing that the programme is on course to succeed. However, serious doubts have been raised, from sources including the Public Accounts Committee, about how much has been achieved and about the likely completion date. In particular, progress on the development of the NCRS has been questioned. (Paragraph 41)

3. During our inquiry, both at home and abroad, similar messages were given to us repeatedly from different sources. We commend these to the Department:

    - The EPR is essential and is the top priority for improving health care.
    - The installation of a comprehensive IT system is a long journey best managed by a staged and piloted development not a big bang approach.
    - The input of end-users is vital in planning, design and implementation.
    - Local flexibility is essential to allowing continued use of effective systems already in place, as is interoperability if local systems are to communicate with one another.
    - As EPR systems make more personal health data accessible to more people, breaches of security and confidentiality must be regarded as serious matters.
    - The support of the public must be obtained. The fact that EPR systems are essential for the delivery of modern health care and can improve communication between different health care staff and between staff and patients must be adequately publicised to users of the NHS. We believe this would help to convince people of the necessity and benefits of the EPR and reduce resistance where it exists. (Paragraph 42)

The Summary Care Record

4. The Committee is pleased that trials of the national Summary Care Record (SCR) are now going ahead following delays to the project. The SCR has the potential to improve the safety and efficiency of care and to make the health service more

patient-centred. The SCR has the potential to improve the safety and efficiency of care especially in emergency situations when care is delivered by staff unfamiliar with the patient involved. The Committee supports the aim of introducing a nationally available summary record as soon as possible and deplores the delays and continuing indecision about its content. (Paragraph 113)

5. The SCR has less comprehensive clinical value than shared Detailed Care Record (DCR) systems and is a comparatively straightforward application which extracts information from existing GP systems, whereas DCR systems must be built up from a range of complex and interdependent component applications. Given that there is expected to be clinical value from the SCR, its roll-out should not be held back by delays to DCR systems. (Paragraph 114)

6. The Committee was dismayed, however, by the lack of clarity about what information will be included in the SCR and what the record will be used for. Officials gave different answers to these questions on different occasions. The Committee was told at various times that the SCR will be used for the delivery of unscheduled care, for the care of patients with long-term conditions, and to exchange information between primary and secondary care. It is little wonder that patient groups expressed confusion about the purpose and content of the SCR. (Paragraph 115)

7. The Committee is aware of the Department's most recent plans but is concerned that the complexity of the SCR appears to be increasing. This will make the SCR more difficult to use, particularly in emergency situations. The Department must be clear about the purpose of the SCR, and it must ensure that the record is easy to use. To this end, we recommend that the SCR include a single standardised front screen to display key health information which is vital for emergency care. (Paragraph 116)

8. The Committee has also received inconsistent information about the patient consent arrangements for the SCR. Initially, we were told that information will be added to the SCR with "implied consent", provided patients do not opt out. This approach was strongly criticised by clinical and patient groups. However, it subsequently became clear that while the creation of the SCR, and the addition of "life-saving" details such as prescription information, will require "implied consent", the addition of detailed clinical information will only take place with "explicit consent" from the patient. This hybrid consent system represents a much more satisfactory model but one which has not been well communicated to patients or clinicians. (Paragraph 117)

9. The inclusion of prescription information on the SCR with only "implied consent" remains problematic, however. On the one hand, prescription information can often make a patient's diagnosis obvious. On the other hand, excluding some prescription information from the SCR would be clinically dangerous. If the Department of Health does use the "implicit consent" model for prescription information, it should make clear to patients the implications both for data privacy and clinical safety. (Paragraph 118)

10. The Committee considers that much of the controversy over privacy and consent arrangements for the SCR would have been avoided if Connecting for Health had

communicated its plans more clearly to patients. We recommend that Connecting for Health:

- Make clear to patients, clinicians and the public that detailed information will only be added to the SCR with explicit patient consent, that patients can see this information before it is added, and that patients can choose to have an SCR created but not accessed beyond their GP surgery; and
- Offer the same assurances to all patients in the SCR early adopter sites. (Paragraph 119)

11. The arrangements for the SCR will be strengthened when "sealed envelopes" are made available to protect sensitive information and when patients can access their record via the HealthSpace website. It is unfortunate that these elements of the SCR are not yet in place, but the Committee understands and supports the decision to press ahead in any case with trials of the SCR. Connecting for Health must ensure that both "sealed envelopes" and HealthSpace are introduced as soon as possible, particularly so that their effectiveness can be assessed during the independent evaluation of the early adopter programme. (Paragraph 120)

12. "Sealed envelopes" are a vital mechanism if sensitive information is to be held on the SCR. We recommend that:

- The right to break the seal protecting information in "sealed envelopes" should only be held by patients themselves, except where there is a legal requirement to override this measure; and
- Information in "sealed envelopes" should not be made available to the Secondary Uses Service under any circumstances; this will allow patients to prevent data being used for research purposes without their consent. (Paragraph 121)

13. HealthSpace is an excellent addition to the SCR programme and has huge potential to improve the safety and efficiency of care by allowing patients to check the accuracy of their SCR and to access detailed information about their own health. In order to take fuller advantage of HealthSpace, we recommend that Connecting for Health:

- Trial the use of HealthSpace for patients, particularly those with long-term conditions, to record their own measurements of key health information;
- Ensure that HealthSpace allows patients to view audit trails, showing who has accessed their SCR record and under what circumstances, and offers mechanisms for investigating inappropriate access;
- Promote the use of HealthSpace, monitor levels of uptake, and ensure that there is equitable access across the country and that coercive access is prevented; and
- Commission an independent evaluation of HealthSpace once the system is widely available. (Paragraph 122)

14. We note that in France patients will own their national summary record. This approach gives patients more control over who can access their record and more opportunity to influence and take control of their own care. We therefore recommend that Connecting for Health consider a similar model for the SCR in England. (Paragraph 123)

15. The Committee does not have the knowledge or expertise to make specific judgements about the likely effectiveness of planned technical security systems at protecting the SCR from external attack. We received strong assurances from officials and suppliers about the quality of security systems, and we accept the inevitability of a trade-off between levels of security and the need to ensure that systems are user-friendly. We also acknowledge that no information storage system can be considered 100% secure. (Paragraph 124)

16. However, serious concerns were expressed regarding the lack of information both about how security systems will work and about the outcomes of security testing. We agree with these concerns and recommend that Connecting for Health ensure that BT's planned security systems for its national applications are subject to independent evaluation and that the outcomes of this are made public. (Paragraph 125)

17. Maintaining the operational security of the new SCR system is a substantial challenge. We acknowledge that Connecting for Health and its suppliers have made significant efforts to minimise the risk of operational security breaches. Individual smartcards, rigorous user authentication, role-based access controls, legitimate relationships and audit trails will all help to increase operational security, both individually and in combination. However, many of these measures are new and untested on the scale that they will be used in the NHS. As a result, their impact and vulnerabilities are difficult to predict. We therefore recommend that Connecting for Health:

    - Ensure that the evaluation of the early adopter sites examines both the individual and the collective impact of the new operational security measures for the SCR, commissioning a separate evaluation if necessary; and

    - Undertake a program of operational security training for all staff with access to the SCR, emphasising the importance of not divulging information to those who request it under false pretexts. (Paragraph 126)

18. Operational security also depends on effective enforcement. The Department of Health and the Information Commissioner's Office have called for custodial sentences for people who unlawfully access personal information. The Committee welcomes this, and recommends that a substantial audit resource be provided to detect and prosecute those who access the system unlawfully. (Paragraph 127)

The Detailed Care Record

Vision and potential

19. Patient record systems which record detailed clinical information that can be shared or joined electronically within and between a range of local organisations are the "holy grail" for NPfIT. Such Detailed Care Record (DCR) systems can bring dramatic improvements to the safety, quality and efficiency of NHS care, not only through faster access to and sharing of patient information, but also by supporting key clinical processes such as imaging and prescribing. More sophisticated clinical systems can further improve care, for example by supporting clinical decision-making and providing automatic messages and alerts to challenge unsafe practices. (Paragraph 227)

20. Achieving the widespread uptake of DCR systems is therefore the single most important advance that the NHS can make towards the provision of faster, better integrated and more patient-centred care. The potential benefits from detailed systems are wider than those offered by the national SCR system. Moreover, the goal of providing DCR systems to all NHS providers in England was clearly set out in the specification document on which NPfIT was based and tendered. It is thus on NPfIT's success in implementing DCR systems that the programme's effectiveness should ultimately be judged. (Paragraph 228)

21. Yet there is a perplexing lack of clarity about exactly what NPfIT will now deliver. It is not clear what information will be recorded and shared on DCR systems, nor the range of organisations that will be able to share information. Suppliers told us there will be significant variation between the size of different areas. The Department stated that DCR systems may be confined to areas as small as a single hospital or as large as an entire SHA. While local control over the new systems is a desirable goal, it is surprising that the architects of the DCR were not able to provide a clearer vision of what is planned. There is an explanatory vacuum surrounding DCR systems and this must be addressed if duplication of effort at a local level is to be avoided. We recommend that Connecting for Health:

    - Publish clear information about its plans for DCR systems, stating in particular what area will be covered by shared records and what degree of information sharing will be possible; these plans should make reference to the original specifications for the Integrated Care Records Service, making clear how the scope of the project has changed since 2003; and

    - Set out clear milestones for achieving the increasing levels of interoperability and automation offered by DCR systems. (Paragraph 229)

Progress and implementation

22. Progress on delivering the various elements of shared DCR systems has varied considerably. Projects such as the N3 network and the deployment of Picture Archiving and Communication Systems are on the way to successful completion: Connecting for Health deserves some credit for these successes. However, the continuing delays to delivering new Patient Administration Systems (PAS) and

functions such as electronic prescribing in hospitals are a major concern. As a result of such delays, the shared DCR remains a distant prospect. Only BT provided an estimate, 2010, of when shared records will be available. This timetable only applies to the London area, however, and the level of information sharing which will be possible by this date was unclear. (Paragraph 230)

23. There have been many causes of the delays in delivering new systems. One of these has been the expansion to the scope of the programme since 2002. Changes were perhaps inevitable given the scale of NPfIT, but it is disappointing that essentially administrative applications such as Choose and Book were given priority ahead of clinically useful DCR systems. It is also apparent that the original timescales for deploying DCR systems were over-ambitious and did not take sufficient account of the complexity of replacing existing systems. The failure to give hospitals responsibility for implementing their own systems, and the lack of focus on changing local working practices to accommodate newly deployed systems, have also caused delays. (Paragraph 231)

24. The lack of progress on implementing new hospital PAS software, which has in turn prevented suppliers from deploying more sophisticated clinical systems, remains the biggest obstacle to delivering shared local records. The implementation of new hospital systems is more than two years behind schedule. In London and the South, where Cerner's Millennium system is to be deployed, there is some evidence of progress, as well as a timetable for completing implementation in London. Yet in the remaining three clusters, which are awaiting iSoft's Lorenzo product, delays drag on. Such delays have left many hospitals relying on increasingly outdated systems for their day-to-day administration. Most worryingly, the failure to deliver systems on time has reduced the confidence of local clinicians and managers in the programme, something which has itself contributed to delays. (Paragraph 232)

25. We recommend that Connecting for Health:

- Ensure that all LSPs publish detailed timetables for delivering new PAS applications, electronic prescribing systems and shared local record systems, indicating what level of information sharing will be possible when DCRs are first implemented; and

- Set a deadline for the successful deployment of the Lorenzo system in an NHS hospital, making clear that if the deadline is not achieved then other systems with similar capability will be offered to local hospitals. (Paragraph 233)

The way forward

26. In light of a range of concerns, including the delays to elements of the DCR programme, a number of witnesses called for an independent review of the whole of NPfIT. Whilst we understand the reasons for this, we do not agree that a comprehensive review is the best way forward. First, many of the questions raised by the supporters of a review would be addressed if Connecting for Health provided the additional information and independent evaluation which we recommend in this

report. Secondly, the programme has already been scrutinised by the National Audit Office, the Public Accounts Committee and ourselves. We therefore recommend that:

- The implementation of DCR systems be addressed in the short term by increasing both the local ownership and the professional leadership of the programme; and
- The ongoing review by Lord Darzi on the future of the NHS include in its remit the long-term prospects for using electronic systems to improve the quality of care, particularly for the growing number of patients with long-term conditions. (Paragraph 234)

27. The Committee recognises the need to maintain a balance between central and local input into the development of DCR systems. We acknowledge the success of NPfIT's national leadership in ensuring economies of scale and effective contract management. However, we disagree that this highly centralised approach is necessary to ensure consistent development of new systems across the NHS, provided that sufficient attention is given to nationally agreed technical and clinical standards. It is also clear that centrally driven implementation of local systems has stifled local activity and caused frustration and resentment at trust level. The successful delivery of DCR systems depends upon the ability of Connecting for Health to harness the benefits from local as well as national input, something which it has not achieved so far. (Paragraph 235)

28. There are already signs of a change of approach to increase local ownership of system implementation. Accountability is being devolved through the NPfIT Local Ownership Programme and control for some users is being increased through GP Systems of Choice. These measures are welcome but overdue. There is a need to go further and faster with reforms of this type. We recommend that:

- Connecting for Health devolve responsibility for performance managing implementation of all NPfIT systems to Strategic Health Authorities (SHAs);
- SHAs devolve responsibility for operational deployment by giving individual hospital trusts control over implementing their own new systems. SHAs should also devolve responsibility for implementing shared record systems across local health communities to their constituent Primary Care Trusts (PCTs);
- SHAs, PCTs and hospital trusts be given the authority to negotiate directly with LSPs and to hold suppliers to account, so that local organisations are not given responsibility without power; and
- Connecting for Health offer all local organisations a choice of systems from a catalogue of accredited suppliers, as far as this approach is possible within the limitations of existing contracts. (Paragraph 236)

29. Connecting for Health's own role should switch as soon as possible to focus on setting and ensuring compliance with technical and clinical standards for NHS IT

systems, rather than presiding over local implementation. Clear standards would allow systems to be accredited nationally but would also ensure that local trusts have a choice of system and control over implementation. (Paragraph 237)

30. Technical standards should cover system security and reliability but should focus in particular on ensuring full interoperability between accredited systems. Comprehensive interoperability standards should guarantee that data can be seamlessly exchanged between systems whilst ensuring that users are not committed to a single supplier. In order to develop transparent technical standards, we recommend that Connecting for Health:

    - Establish an independent technical standards body responsible for setting the interoperability requirements for data exchange for all systems deployed in the NHS. These standards should be published and subjected to full external scrutiny;

    - Require all system suppliers to the NHS to meet and demonstrate conformity with these standards. Systems should be "kite marked" or classified to give details of their compatibility; and

    - Work with industry and academia to establish an independent technical standards testing service to evaluate and accredit systems for use in the NHS. (Paragraph 238)

31. Safe and effective data sharing, the fundamental aim of DCR systems, also requires a more standardised approach to the recording of clinical information. Such an approach is at the heart of ensuring real interoperability between systems and is vital if data from DCR systems is to be used as a basis either for the SCR or for research. The NHS Data Dictionary and the SNOMED CT coding system are important to achieving more consistent recording of patient information. We recommend that Connecting for Health publish a timetable for introducing SNOMED CT across the NHS. (Paragraph 239)

32. But Connecting for Health must do much more to ensure that the recording of detailed clinical data is standardised. Professionally developed datasets and agreed approaches to the structure and content of detailed records are urgently needed for each of the main clinical specialties and for use in a range of different care settings. Developing such standards will require close collaboration with Royal Colleges and other professional bodies. We recommend that Connecting for Health work with professional groups to:

    - Identify the information standards which will be required within their specialty area; and

    - Develop and implement consensus-based clinical information standards. (Paragraph 240)

33. Separate clinical records on an individual patient can only be combined safely if each person can be accurately identified. The introduction of the new NHS number as the unique patient identifier and its allocation at birth through NHS Numbers for Babies

is therefore a significant achievement. Yet the value of this work and the future integrity of clinical information will be undermined if organisations are unable to retrieve an individual's NHS number when they need to use it or to allocate temporary NHS numbers for use in emergencies. We recommend that:

- The Department of Health set a timetable for mandating the use of the correct NHS number on all clinical communications, and make this a performance measure for all NHS organisations;
- Processes are introduced to allow temporary NHS numbers to be allocated which can subsequently be reconciled with the patient's permanent NHS number through the Personal Demographic Service; and
- Systems are maintained to treat patients under a separate, pseudonymous NHS number where this is necessary. (Paragraph 241)

Security, reliability and consent

34. The resilience of new systems will be enhanced by distributing data across a range of hosting centres. Suppliers assured us that systems will be distributed in this way but the impact of the power failure at the Maidstone data centre, which affected 80 trusts, suggests otherwise. We recognise that lessons have been learned from the Maidstone incident. Nonetheless, we recommend that Connecting for Health instruct suppliers to publish details of all significant reliability problems along with a full incident log. (Paragraph 242)

35. The sharing of unique smartcards between users is unacceptable and undermines the operational security of DCR systems. However, we sympathise with the A&E staff who shared smartcards when faced with waits of a minute or more to access their new PAS software. Unless unacceptably lengthy log-on times are addressed, security breaches are inevitable. We recommend that Connecting for Health:

    - Ensure that suppliers have clear plans for achieving access times compatible with realistic clinical requirements for all of their systems; and
    - Continue to monitor the potential for introducing more sophisticated access systems, such as facial pattern recognition, in busy areas such as A&E. (Paragraph 243)

36. The Department has indicated that explicit consent will be required before DCR information can be shared between separate organisations. The Committee supports this approach and recommends that the consent model for the shared DCR be communicated to patients as clearly and as early as possible. (Paragraph 244)

37. However, if sensitive information is to be stored and shared on DCR systems, it is important that local "sealed envelope" systems are developed and tested as soon as possible. We were concerned to hear that suppliers have not yet received specifications for local "sealed envelopes". We recommend that Connecting for Health provide such specifications as a matter of urgency and set a clear timetable for the introduction of this technology at a local level. (Paragraph 245)

The Secondary Uses Service

38. The Secondary Uses Service (SUS), which succeeded the NHS-Wide Clearing Service, has for some years helped to improve the health service by providing access to and analysis of data for commissioning, management and audit purposes. However, the development of the SCR and DCR will allow access to clinical data which are timelier, better integrated and of a profoundly higher quality than those currently available. This will transform the SUS and offers significant benefits, most notably for health research. In particular, if the highly detailed data captured by DCR systems can be made available through the SUS then the possibilities for new and improved research are outstanding. (Paragraph 280)

39. The Department has acknowledged the need to take advantage of the research opportunities offered by the SUS and has established a partnership with the UK Clinical Research Collaboration to achieve this. We welcome this, but researchers nevertheless told us that much more could be done to maximise these opportunities. We recommend that Connecting for Health:

    - Mandate the use of the unique patient identifier, the NHS number, in all health service interactions in England;
    - Develop appropriate linkage between databases within and beyond the SUS. This would also have benefits for non-research activities such as health protection;
    - Ensure that the development of clinical information standards, which we recommended in Chapter 4, takes account of the needs of research; and
    - Initiate a campaign of public engagement so that both the opportunities and risks from using health data for research purposes are better understood. (Paragraph 281)

40. Increasing access to health data brings new challenges for safeguarding patient privacy. It is therefore vital that the systems which regulate availability of, and access to, data through the SUS are safe and effective. Governance systems must strike a difficult balance between the need to protect patient privacy and the need to take advantage of the increasing availability of data, between safeguarding individual rights and promoting the public good. Unless such a balance can be struck, there is a risk either that the potential of the SUS will not be realised, or that public confidence will be damaged. (Paragraph 282)

41. There are a number of weaknesses within current access and governance systems. While explicit patient consent is the ideal means of allowing access to data, it is often impossible to ask for consent in practice, particularly for studies using historical data. Pseudonymisation is a good idea in principle, but full pseudonymisation is only possible in some situations because potentially identifying data are often needed for effective research. It follows that some research will continue to require access to partially pseudonymised data in situations where obtaining explicit consent is impossible. However, the Patient Information Advisory Group (PIAG), which

considers such requests, remains a temporary body. PIAG has attracted criticism both for its processes and for its decisions. (Paragraph 283)

42. There is an urgent need to address these problems, especially as the amount and type of data potentially available through the SUS will proliferate rapidly in future. We recommend that the Department of Health conduct a review of both national and local procedures for controlling access to electronic health data for "secondary" uses. In particular, the review should examine:

- How best to balance the opportunity to improve access to data for research purposes with the ongoing need to safeguard patient privacy;
- Whether to establish a national Information Governance Board to oversee the arrangements for access to data for secondary uses;
- The case for establishing a permanent body to succeed the Patient Information Advisory Group and whether this should be a subcommittee of the national Board;
- The effectiveness of the pseudonymisation process proposed by Connecting for Health and its suppliers, which should be subject to independent public evaluation;
- What compensating controls, such as third party brokerage, should be used to protect patient privacy in situations where research must be conducted with partially rather than fully pseudonymised information; and
- How governance arrangements for access to data for research purposes should differ from those which apply to other "secondary" purposes, such as immigration and counter-terrorism. (Paragraph 284)

Glossary

AMS	Academy of Medical Sciences
BMA	British Medical Association
CfH	Connecting for Health
CHI	Canada Health Infoway
CSC	Computer Sciences Corporation
DCR	Detailed Care Record
DH	Department of Health
DMP	Dossier Médicale Personnel
e-GIF	e-Government Interoperability Framework
EPR	Electronic Patient Record
ETP	Electronic Transfer of Prescription
FIPR	Foundation for Information Policy Research
GPSoC	GP Systems of Choice
HES	Hospital Episode Statistics
ICO	Information Commissioner's Office
LSP	Local Service Provider
N3	The New National Network for the NHS
NAO	National Audit Office
NCRS	NHS Care Records Service
NLOP	NPfIT Local Ownership Programme
NPfIT	National Programme for IT in the NHS
NWCS	NHS-Wide Clearing Service
PACS	Picture Archiving and Communication System
PAS	Patient Administration System
PCT	Primary Care Trust
PDS	Personal Demographics Service
RCP	Royal College of Physicians
SCR	Summary Care Record
SHA	Strategic Health Authority
SNOMED CT	Systematised Nomenclature of Medicine Clinical Terms
SUS	Secondary Uses Service
UKCRC	UK Clinical Research Collaboration / UK Computing Research Committee

Formal minutes

Wednesday 25 July 2007

Members present:

Mr Kevin Barron, in the Chair

Mr David Amess	Dr Doug Naysmith
Charlotte Atkins	Mike Penning
Mr Ronnie Campbell	Mr Lee Scott
Jim Dowd	Dr Howard Stoate
Sandra Gidley	Dr Richard Taylor

Draft Report (*The Electronic Patient Record*), proposed by the Chairman, brought up and read.

Motion made, and Question proposed, That the draft Report be read a second time, paragraph by paragraph.—(*The Chairman.*)

The Committee divided,

Ayes, 7	Noes, 3
Charlotte Atkins	Mr David Amess
Mr Ronnie Campbell	Mike Penning
Jim Dowd	Mr Lee Scott
Sandra Gidley	
Dr Doug Naysmith	
Dr Howard Stoate	
Dr Richard Taylor	

Paragraphs 1 to 284 read.

Motion made, and Question proposed, That paragraphs 1 to 284 stand part of the Report.—(*The Chairman.*)

The Committee divided,

Ayes, 7	Noes, 3
Charlotte Atkins	Mr David Amess
Mr Ronnie Campbell	Mike Penning
Jim Dowd	Mr Lee Scott
Sandra Gidley	
Dr Doug Naysmith	
Dr Howard Stoate	
Dr Richard Taylor	

Summary read.

Motion made, and Question proposed, That the Summary be agreed to.—(*The Chairman.*)

The Committee divided,

Ayes, 7	Noes, 3
Charlotte Atkins	Mr David Amess
Mr Ronnie Campbell	Mike Penning
Jim Dowd	Mr Lee Scott
Sandra Gidley	
Dr Doug Naysmith	
Dr Howard Stoate	
Dr Richard Taylor	

Motion made, and Question proposed, That the Report be the Sixth Report of the Committee to the House.—(*The Chairman.*)

The Committee divided,

Ayes, 7	Noes, 3
Charlotte Atkins	Mr David Amess
Mr Ronnie Campbell	Mike Penning
Jim Dowd	Mr Lee Scott
Sandra Gidley	
Dr Doug Naysmith	
Dr Howard Stoate	
Dr Richard Taylor	

Ordered, That the Chairman make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

Several Memoranda were ordered to be reported to the House for printing with the Report.

Several Memoranda were ordered to be reported to the House for placing in the Library and Parliamentary Archives.

[Adjourned till Thursday 11 October 2007 at 9.30am

Witnesses

Thursday 26 April 2007

Page

Richard Granger, Director General of IT for the NHS, **Harry Cayton**, National Director for Patients and the Public, Department of Health, and **Dr Gillian Braunold**, National Clinical Lead for GPs, Connecting for Health — Ev 1

Dr Paul Cundy, Chair, General Practitioners' Joint IT Committee, **Dr Martyn Thomas**, visiting Professor of Software Engineering, University of Oxford, and **Andrew Hawker**, NHS patient — Ev 20

Thursday 10 May 2007

Professor Douwe Korff, Professor of International Law, London Metropolitan University, **Joyce Robins**, Co-Director, Patient Concern, and **Jonathan Bamford**, Assistant Information Commissioner, Information Commissioner's Office — Ev 35

Guy Hains, President, Europe Group, Computer Sciences Corporation, **Professor Brian Randell**, Professor of Computing Science, University of Newcastle, and **Dr Rob Hale**, Confidentiality Working Group, Royal College of Psychiatrists — Ev 51

Thursday 7 June 2007

Professor Simon Wessely, Academy of Medical Sciences, **Dr Mark Walport**, Director, The Wellcome Trust, and **Professor Carol Dezateux**, Head of the MRC Centre for Paediatric Epidemiology and Biostatistics, Institute of Child Health — Ev 64

Patrick O'Connell, Managing Director, BT Health, **Alan Shackman**, Independent IT Consultant, and **Professor Naomi Fulop**, Chair of Health and Health Policy, King's College London — Ev 74

Thursday 14 June 2007

Professor John Feehally, President, The Renal Association, **Dr Gill Markham**, Vice President, The Royal College of Radiologists, and **Frank Burns**, Former CEO, Wirral Hospital NHS Trust — Ev 90

Lord Hunt of Kings Heath, Minister of State for Quality, **Richard Granger**, Director General of IT for the NHS, and **Dr Simon Eccles**, National Clinical Lead for Hospital Doctors, Department of Health — Ev 101

List of written evidence (HC 422–III)

1	Department of Health (EPR 01A)	Ev 117
2	Department of Health (EPR 01C)	Ev 123
3	Professor Brian Randell (EPR 20A)	Ev 124
4	BT Health (EPR 51A)	Ev 126
5	Dr Paul Cundy (EPR 73)	Ev 128
6	Dr Paul Cundy (EPR 73A)	Ev 130
7	Dr Chris Pounder (EPR 74)	Ev 132
8	Professor Naomi Fulop, King's College London (EPR 75)	Ev 133
9	Department of Health (EPR 01D)	Ev 142
10	Department of Health (EPR 01E)	Ev 147

List of written evidence (HC 422–II)

1	Department of Health (EPR 01)	Ev 01
2	Academy of Medical Sciences (EPR 34)	Ev 12
3	Alliance Boots plc (EPR 27)	Ev 15
4	Association of the British Pharmaceutical Industry (ABPI) (EPR 39)	Ev 17
5	ABDO, AOP and FODO (EPR 44)	Ev 19
6	Association of Directors of Social Services (ADSS) and Association of Directors of Children's Services (ADCS) (EPR 21)	Ev 20
7	Association of Independent Multiple Pharmacies, the Company Chemists Association, the National Pharmacy Association and the Pharmaceutical Services Negotiating Committee (EPR 22)	Ev 23
8	Association for Clinical Biochemistry (EPR 36)	Ev 27
9	Breakthrough Breast Cancer (EPR 32)	Ev 31
10	British Association for Community Child Health (EPR 16)	Ev 34
11	British Computer Society (BCS) (EPR 66)	Ev 36
12	British in Vitro Diagnostics Association (BIVDA) (EPR 33)	Ev 40
13	British Medical Association (EPR 40)	Ev 41
14	British Psychological Society (EPR 45)	Ev 45
15	BT (EPR 51)	Ev 47
16	Computer Sciences Corporation (CSC) (EPR 46)	Ev 51
17	Computer Weekly (EPR 64)	Ev 54
18	Diabetes UK (EPR 54)	Ev 55
19	Dignity in Dying (EPR 49)	Ev 58
20	Faculty of Family Planning and Reproductive Health Care (EPR 18)	Ev 62
21	Foundation for Information Policy Research (EPR 61)	Ev 63
22	General Medical Council (EPR 69)	Ev 66
23	Health Protection Agency (EPR 31)	Ev 68
24	Help the Aged (EPR 63)	Ev 69

25	Information Commissioner (EPR 24)	Ev 70
26	Intellect (EPR 67)	Ev 73
27	Londonwide LMCs (EPR 41)	Ev 75
28	Medical Protection Society (EPR 55)	Ev 76
29	NHS Alliance (EPR 19)	Ev 79
30	NHS Confederation (EPR 57)	Ev 82
31	Patient Concern (EPR 11)	Ev 85
32	Press For Change (EPR 060	Ev 87
33	Renal Association and the Renal Information Exchange Group (EPR 30)	Ev 89
34	Royal College of General Practitioners (EPR 17)	Ev 93
35	Royal College of Nursing (EPR 47)	Ev 95
36	Royal College of Paediatrics and Child Health (EPR 59)	Ev 99
37	Royal College of Physicians (EPR 48)	Ev 100
38	Royal College of Psychiatrists (EPR 25)	Ev 103
39	Royal College of Radiologists (EPR 35)	Ev 105
40	Royal College of Surgeons of England (EPR 26)	Ev 106
41	Royal Pharmaceutical Society of Great Britain (RPSGB) (EPR 56)	Ev 109
42	Socialist Health Association (EPR 62)	Ev 111
43	South East Health Ltd (EPR 13)	Ev 112
44	Stalis Ltd (EPR 05)	Ev 114
45	Symantec (EPR 37)	Ev 118
46	UK Clinical Research Collaboration (EPR 52)	Ev 121
47	UK Computing Research Committee (EPR 29)	Ev 124
48	Wellcome Trust (EPR 42)	Ev 126
49	Nicholas Beale (EPR 14)	Ev 129
50	Mr Tom Brook (EPR 70)	Ev 131
51	Dr Gerard Bulger (EPR 28)	Ev 137
52	Frank G Burns (EPR 60)	Ev 141
53	Dr Sarah Dilks (EPR 10)	Ev 145
54	Peter Fairbrother (EPR 43)	Ev 146
55	Dr Peter Gooderham (EPR 08)	Ev 149
56	Robin Guenier (EPR 23)	Ev 153
57	Andrew Hawker (EPR 15)	Ev 159
58	Ms A Jones (EPR 07)	Ev 160
59	Jon Orrell (EPR 53)	Ev 162
60	Ivor Perry (EPR 58)	Ev 163
61	Professor Brian Randell (EPR 20)	Ev 164
62	Dr Maurice H Rosen (EPR 12)	Ev 168
63	Mr Norman Sanders (EPR 71)	Ev 170
64	Alan Shackman (EPR 38)	Ev 177
65	Dr Peter Smith (EPR 03)	Ev 182
66	James Stuart (EPR 02)	Ev 183
67	Dr Paul Thornton (EPR 50)	Ev 186
68	Helen Wilkinson (EPR 65)	Ev 190

List of unprinted evidence

The following memoranda have been reported to the House, but to save printing costs they have not been printed and copies have been placed in the House of Commons Library, where they may be inspected by Members. Other copies are in the Parliamentary Archives, and are available to the public for inspection. Requests for inspection should be addressed to The Parliamentary Archives, Houses of Parliament, London SW1A 0PW (tel. 020 7219 3074). Opening hours are from 9.30 am to 5.00 pm on Mondays to Fridays.

Breakthrough Breast Cancer (EPR 32A)

Computer Sciences Corporation (CSC) (EPR 46A)

Dr Thornton (EPR 50A)

Dr Thornton (EPR 50B)

Robert Erskine (EPR 68)

Rachel Gould (EPR 72)

Sufferers of Iatrogenic Neglect (EPR 77)

Action on Rights for Children (EPR 80)

Patient Information Advisory Group (EPR 81)

Reports from the Health Committee

The following reports have been produced by the Committee in this Parliament. The reference number of the Government's response to the Report is printed in brackets after the HC printing number.

Session 2006–07

First Report	NHS Deficits	HC 73 (Cm 7028)
Second Report	Work of the Committee 2005–06	HC 297
Third Report	Patient and Public Involvement in the NHS	HC 278 (Cm 7128)
Fourth Report	Workforce Planning	HC 171 (Cm 7085)
Fifth Report	Audiology Services	HC 392 (Cm 7140)

Session 2005–06

First Report	Smoking in Public Places	HC 436 (Cm 6769)
Second Report	Changes to Primary Care Trusts	HC 646 (Cm 6760)
Third Report	NHS Charges	HC 815 (Cm 6922)
Fourth Report	Independent Sector Treatment Centres	HC 934 (Cm 6930)

The following reports have been produced by the Committee in the 2001–05 Parliament.

Session 2004–05

First Report	The Work of the Health Committee	HC 284
Second Report	The Prevention of Thromboembolism in Hospitalised Patients	HC 99 (Cm 6635)
Third Report	HIV/AIDS and Sexual Health	HC 252 (Cm 6649)
Fourth Report	The Influence of the Pharmaceutical Industry	HC 42 (Cm 6655)
Fifth Report	The Use of New Medical Technologies within the NHS	HC 398 (Cm 6656)
Sixth Report	NHS Continuing Care	HC 399 (Cm 6650)

Session 2003–04

First Report	The Work of the Health Committee	HC 95
Second Report	Elder Abuse	HC 111 (Cm 6270)
Third Report	Obesity	HC 23 (Cm 6438)
Fourth Report	Palliative Care	HC 454 (Cm 6327)
Fifth Report	GP Out-of-Hours Services	HC 697 (Cm 6352)
Sixth Report	The Provision of Allergy Services	HC 696 (Cm 6433)

Session 2002–03

First Report	The Work of the Health Committee	HC 261
Second Report	Foundation Trusts	HC 395 (Cm 5876)
Third Report	Sexual Health	HC 69 (Cm 5959)
Fourth Report	Provision of Maternity Services	HC 464 (Cm 6140)
Fifth Report	The Control of Entry Regulations and Retail Pharmacy Services in the UK	HC 571 (Cm 5896)
Sixth Report	The Victoria Climbié Inquiry Report	HC 570 (Cm 5992)

Seventh Report	Patient and Public Involvement in the NHS	HC 697 (Cm 6005)
Eight Report	Inequalities in Access to Maternity Services	HC 696 (Cm 6140)
Ninth Report	Choice in Maternity Services	HC 796 (Cm 6140)

Session 2001–02

First Report	The Role of the Private Sector in the NHS	HC 308 (Cm 5567)
Second Report	National Institute for Clinical Excellence	HC 515 (Cm 5611)
Third Report	Delayed Discharges	HC 617 (Cm 5645)

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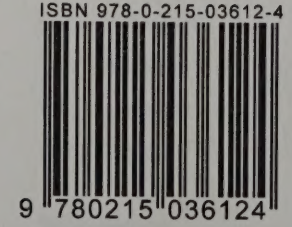

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